

UNDERSTANDING CIRCUMSCRIBED INTERESTS IN INDIVIDUALS WITH  
AUTISM-SPECTRUM DISORDERS AND HOW THEY RELATE TO FAMILIES

by

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## Abstract

Autism-spectrum disorders (ASDs) are a group of neurodevelopmental disorders that are becoming increasingly more prevalent. A diagnostic criterion for autism is the presence of restricted, repetitive behaviours (RRBs), one of which is the intense fascinations for virtually any topic: circumscribed interests (CIs). CIs have the potential to be used for motivational purposes. This study employed semi-structured interviews using Interpretative Phenomenological Analysis (IPA) with individuals with ASDs and their parents. In total, 11 families participated in this study, comprising 33 individuals (16 parents and 17 individuals with ASDs). This study found five themes: He's Very Unique; They Don't Realize that Not Everyone Lives and Thinks the Same Thing All the Time; We Couldn't even Pronounce the Names of These Dinosaurs, and Jason was Telling Us; You Can't Change Them, You Can Only Love Them; and So I Can Do My Job at the Same Time and Observe the Weather at the Same Time.

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- in this age, as opposed to less enlightened times, where we as a species are moving towards liberty, respect for individuals, the abandonment of bigotry and ignorance,
- in a democracy, with somewhat decent economic circumstances, one not utterly ruled by the whims of despots and totalitarians,
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# UNDERSTANDING CIRCUMSCRIBED INTERESTS IN INDIVIDUALS WITH AUTISM-SPECTRUM DISORDERS AND HOW THEY RELATE TO FAMILIES

## Chapter 1: Introduction

Autism is a developmental disorder comprising of qualitative impairments and deficits in two critical areas – social integration and communication, and the presence of restricted and repetitive behaviours (RRBs) and stereotyped patterns of behaviour, activities, and interests; as well as delays or abnormal functioning in social interaction, language used in communicating with others, and imaginative play, and can be distinguished from related disorders (American Psychiatric Association, 2000). Autism (also known as Autistic Disorder) is categorized as one of five Pervasive Developmental Disorders (PDDs) in the *Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> Edition, Text Revision* (DSM-IV-TR) (APA, 2000), along with Asperger's Syndrome (AS), Rett's Syndrome, Childhood Disintegrative Disorder (CDD), and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).

Autism and related syndromes and disorders are also referred to in the literature collectively as Autism-Spectrum Disorders (ASDs). Individuals with ASDs can vary in the severity, or intensity, of how their particular condition impacts and affects them: these individuals can vary from lower-functioning (severely affected) to higher-functioning (less affected) (please refer to page 10 for more details). People with high-functioning autism (HFA) are more similar to the population of typical-developing individuals as they are less severely affected by their condition(s) and appear to be less “different” from the mainstream population of humans.

This study focuses on a particular phenomenon of RRBs referred to as Circumscribed Interests (CIs). CIs are interests that are unusual because of how strong they

are and/or what the topic of the interest is (Boyd, Conroy, Mancil, Nakao, & Alter, 2007) and have amazing abilities in memorization of knowledge related to the interests (Klin, Danovitch, Merz, & Volkmar, 2007). They have the capacity to interfere with such aspects of life as social development (Boyd et al., 2007; Klin et al., 2007; South, Ozonoff, & McMahon, 2005), and learning/memory (Klin et al., 2007). CIs have been viewed as nuisances and hindrances up until recent years when the academic zeitgeist began to turn towards embracing CIs (Mercier, Mottron, & Belleville, 2000). Since the turn of the millennium, numerous studies have begun to emerge stating that CIs should not be cast aside as they are important aspects of the lives of individuals with ASDs, and also because they have the potential to be used to encourage desired behaviours (Mercier et al., 2000; Winter-Messiers, 2007).

### *The Nature of ASDs*

ASDs are a continuum of early-onset disorders that are neurodevelopmental in origin – they involve a problem with the development of proper brain functions and behaviours during the individual's life (Matson & LoVullo, 2008). The first major developmental difference between individuals with autism and those without it is rapid early brain growth, with atypical development of areas of the brain that correspond to the diagnostic features of autism, leaving altered structure and function when compared to individuals without ASDs (Baron-Cohen & Klin, 2006). Some of the areas affected include the amygdala and regions of the prefrontal cortex, such as the orbitofrontal and ventromedial cortices, which deal with emotions, socialization, judgement-making, and theory of mind (Baron-Cohen & Klin, 2006; Fellows & Farah, 2007; Hardan et al., 2006). Theory of mind refers to one's ability to conceive other people's mental states, such as feelings, wants, and beliefs (Baron-Cohen, Leslie, & Frith, 1985). Baron-Cohen et al.

(1985) demonstrated that the concept of the theory of mind is one that is distinct from intellectual impairments and is unique to autism, as the typical-developing children and children with Down Syndrome they used as controls could attribute the beliefs of others. The children with autism, who were also older than their control cohorts, could not attribute the beliefs of others. Children with ASDs lack a theory of mind, and therefore have a more difficult time understanding other people and that other people think differently from them.

ASDs are part of a continuum of disorders and syndromes that range in severity from a lower-functioning or severe impairment to a higher-functioning or mild impairment. As the term “spectrum” suggests, it is used to demonstrate the variation in observed symptoms that many individuals with autism, AS, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) can have (Ring, Woodbury-Smith, Watson, Wheelwright, & Baron-Cohen, 2008). Autism, AS, and PDD-NOS are the syndromes that comprise the autism-spectrum, according to the background provided by Ring et al. (2008), and this “definition” is supported by Souders et al. (2009). Matson and LoVullo (2008) have a similar view, though the background they provide includes Rett's Syndrome and Childhood Disintegrative Disorder (CDD); otherwise, Matson and LoVullo (2008)'s definition of ASD is identical to the syndromes comprising the classification of Pervasive Developmental Disorder (PDD) in the DSM-IV-TR (APA, 2000). Ring et al. (2008) also point out that there is debate in the literature about whether the spectrum is a single construct based on gradated severity, or if it is composed of multiple overlapping and related subgroups.

Autism and related syndromes are described by the DSM-IV-TR, where they are categorized under the diagnosis of PDD (APA, 2000). This grouping includes autistic

disorder, AS, Rett's Syndrome, CDD, and PDD-NOS. PDDs are characterized by severe and pervasive impairment in numerous developmental areas, including communicative and social interaction skills, or the presence of restricted and repetitive behaviours (RRBs), and are relative to the individual's mental age (APA, 2000; Klin et al., 2007). More severe forms of autism are often accompanied by intellectual disability, and other characteristics can include challenges with imagination (APA, 2000). To avoid confusion regarding the various initialisms used in this document, please refer to Table 1 below.

*Table 1: Initialisms for Key Terms*

<b>Initialism</b>	<b>Term</b>
ASD	Autism-Spectrum Disorder
AS	Asperger's Syndrome
PDD	Pervasive Developmental Disorder
CDD	Childhood Disintegrative Disorder
PDD-NOS	Pervasive Developmental Disorder Not Otherwise Specified
NDD	Neurodevelopmental Disorder
DD	Developmental Disability
TD	Typically-Developed or Typically-Developing
HFA	High-Functioning Autism
RRB	Restricted, Repetitive Behaviour
SIB	Self-Injurious Behaviour
CI	Circumscribed Interest

While autism and AS will be described in greater length due to their relatively higher occurrence in the population as well as being the primary diagnoses of the participants in this study, the other PDDs will be described briefly. Rett syndrome shares several key social and mental impairments with Autistic Disorder, but occurs predominantly in females, and also involves a loss of hand abilities, deceleration of head

growth, and difficulties in moving the body (APA, 2000). Childhood Disintegrative Disorder, according to the DSM-IV-TR (APA, 2000) is a disorder that includes regression in verbal and nonverbal communication, social relationships, play, and adaptive behaviours after about two years of typical development (and prior to the age of 10); Childhood Disintegrative Disorder differs from autism mainly in terms of when the delays begin to occur, as developmental issues are noted in autism within the first year (APA, 2000).

There are also several conditions that are persistent and occur in concurrence with an ASD: for example, medical conditions, such as chromosomal abnormalities and abnormalities of the central nervous system are possible (APA, 2000). Other concurrent conditions can include seizures, sleep disturbances, gastrointestinal problems, and problems with immune function (Newschaffer et al., 2007). The mechanism linking autism and the immune system is still unknown due to limitations in what data are available, and a lack of data about the neurodevelopmental genesis of autism (Newschaffer et al., 2007). Intellectual impairment is also possible (APA, 2000; Newschaffer et al., 2007), comprising about 40%-55% of cases (Newschaffer et al., 2007). Other possible psychiatric conditions can include mood disorders, such as anxiety or depression, which may be caused by the neurological and/or social deficits of having an ASD, or by a co-morbid mood disorder (Bradley & Burke, 2002; Newschaffer et al., 2007).

The broad range of diagnosis for ASDs makes it difficult for a simple label to properly describe an individual. Labelling is further confounded by the fact that individuals can be more negatively affected or have little visible negative effects whatsoever. Asperger's Syndrome, by contrast, is on the higher-functioning end of the autism spectrum. Individuals with AS show at or above average intelligence, but do not display developmental delay or delayed communication (Baron-Cohen & Klin, 2006). Hans

Asperger, for whom the syndrome is named, noted that the interests of his young patients were more on a specific topic and that his patients accrued massive amounts of information for that topic. These factoid accumulations contrast with Leo Kanner's patients, who Kanner found had a wider array of skills and considerable ability in recalling events, names, texts, or sequential patterns. Individuals with AS have a higher level of CIs (Kleinhans, Akshoomoff, & Delis, 2005).

ASDs have become much more prominent since they were first described in the 1940s. According to the Centers for Disease Control and Prevention (CDC) in the United States, ASDs are estimated to have had a prevalence of 11.3 per 1,000 (one in every 88) eight-year-old children in the year 2008, and have risen significantly in the past decade (CDC, 2012). In the year 2000, the rate of autism prevalence was 6.7 per 1,000 children aged eight-years-old, and has increased with almost every study since then (2002: 6.6 per 1,000; 2004: 8.0 per 1,000; 2006: 9.0 per 1,000). The CDC points out that there was a 23% growth between 2006 and 2008, and a 78% growth between 2002 and 2008. In Canada, according to the National Epidemiologic Database for the Study of Autism in Canada (NEDSAC), the provinces of Newfoundland and Labrador, Prince Edward Island (PEI), and southeastern Ontario were compared between the years 2003 and 2008 (Newfoundland and Labrador) and 2003 and 2010 (PEI and southeastern Ontario) (NEDSAC, 2012). All three locations had an increase in prevalence in all five groups examined (2-4 years, 5-9 years, 10-14 years, girls, and boys), with the largest increases occurring in southeastern Ontario (204% increase in 10-14 years, 170% in 2-4 years, and 161% in girls). In both the CDC (2012) study and the NEDSAC (2012) study, the results should not be generalized to the entire population of individuals with ASDs across Canada and the United States.

While there is much debate about whether the increase in prevalence of ASDs is due to improved diagnostic ability, to an actual increase in the population, or to both, the result is that more people are diagnosed with some form of ASD and more parents are faced with raising a child with such a condition. The increase in the prevalence of autism in previous decades – as demonstrated by Newschaffer et al. (2007) – has expanded to such a degree that the topic of autism has a sizable presence among the lay public. In turn it has become more apparent that autism has become more acknowledged, leading to greater exposure in the media and culture at large. Films such as *Rain Man* and *Mozart and the Whale* feature major characters with an ASD. Television programs such as *The Big Bang Theory*, *Community*, and *House, MD* have main characters who either display signs or symptoms associated with ASDs, or have hinted that certain characters may have an ASD. The mid-season premier of the fifteenth season of *South Park* featured AS as an initial plot point, with one of the main characters being misdiagnosed with the syndrome, and two of the other main characters debating and commenting on the etymology of the eponym. This phenomenon is not limited to American media, as foreign media have addressed the topic as well, such as the Japanese manga series *With the Light*, where a young couple (particularly the mother) and their firstborn son, who is profoundly affected with an ASD, are the central characters.

### *Autism and sleep*

Of the various pathologies that have a comorbid relationship with autism and ASDs, sleep has been a particular problem for individuals with ASDs, particularly children. This relationship is of considerable interest, and while it was not within the scope of this study and its purposes, the importance of this issue requires notation nonetheless as sleep issues may have a substantial impact on individuals with ASDs and their families.

Sleep problems are one of several conditions that can be concurrent with autism, as well as immune function problems, gastrointestinal problems, and seizures (Newschaffer et al., 2007). As sleep problems are also found in the population that does not have developmental disabilities, the extent to which this is the result of, and/or exacerbated by, ASD pathology, and whether it is a common problem for all children within specific age groups, should be distinguished (Souders et al., 2009; Tudor et al., 2012). The evidence in the academic literature strongly suggests that there are issues involving sleep for children with ASDs that are not present in their typically-developing peers.

Employing the Children's Sleep Habits Questionnaire (CSHQ; Owens, Spirito, and McGuinn, 2000) as well as parental reports and actigraphic data, Souders et al. (2009) found that sleep problems were more frequent in an ASD sample compared to a TD sample 45% of the TD group had insomnia, as measured by the CSHQ, and 45.9% of the time according to actigraphic data; comparatively, 66.1% of the ASD group had insomnia according to the CSHQ and 66.7% according to actigraphic data.

The differences between individuals with ASD and TD in terms of sleep brings up the question of why these problems are occurring more in individuals with ASDs. Of the individuals with ASDs who had insomnia in the Souders et al. (2009) study, the causes of the insomnia were determined to be: 15% due to medical reasons; 23% due to medication; 31% due to behavioural insomnia (sleep-association) (the children required their parents' presence and touch to fall asleep); 15% due to behavioural insomnia (limit-setting) (poor consistency with their bedtime routines, though parents attempted to correct this); two of the children had poor sleep hygiene, such as drinking caffeinated beverages before bed and sleeping outside of their beds; 10% were due to other reasons (one from sleep-disordered breathing and three from night terrors). Of these individuals, 11 had good sleep rou-



tines/hygiene; no other factors could account for their sleep problems, other than their neurodevelopmental condition.

Corroborating on whether or not the autism is at fault for sleep problems, Tudor, Hoffman, and Sweeney (2012) assessed the problems of sleep difficulties in children with autism who had no comorbid DD diagnoses, and who had no other ASD or PDD. The authors used data provided by maternal self-reports as well as scores from the CSHQ and the Gilliam Autism Rating Scale – Second Edition (GARS-2; Gilliam, 2006). Significant correlations were found on these two measures: the GARS-2's four criteria (Communication, Social Interaction, Stereotyped Behaviour, and Autism Index (AI) – a measure of autism severity) significantly correlated with the CSHQ's sleep onset delay, sleep duration, and total sleep disturbance subscales; the parasomnias subscale significantly correlated with the GARS-2's Communication, Social Interaction, and AI subscales; the night-waking and sleep disordered breathing subscales significantly correlated with the GARS-2's Social Interaction subscale. Sleep-onset delay was the most predictive value of the Stereotyped Behaviour, Social Interaction, and AI subscales; night-wakings were the second strongest predictor of Social Interaction; sleep anxiety and parasomnias were the strongest predictors of Communication. Both Souders et al. (2009) and Tudor et al. (2012) strongly point out that the sleep problems of the children with ASDs in their studies problems that were related to their neurological condition.

The effects that these problems with sleep have on children with ASDs ranges. In Souders et al. (2009)'s study, the parents with children with ASDs reported that their children had longer sleep latencies, shorter sleep length, more episodes of nighttime awakenings, more sleep anxiety, and more parasomnias, of which only sleep terrors, bed-wetting, and bruxism had significant differences with the TD group (Souders et al., 2009). Wil-

liams, Sears, and Allard (2004) investigated the sleep habits of children with autism (as well as some participants with AS and PDD-NOS) via parent-report questionnaires. While they did find that most of the children slept for at least 5 hours each night, and only 10% sleeping for 4-5 hours, there were still sleep problems: the most prominent were difficulty falling asleep (53%), restless sleep (40%), unwillingness to fall asleep in own bed (40%), frequent nighttime awakenings (34%), and difficulty being aroused from sleep (32%). Dividing the participants into those with intellectual impairments and those without intellectual impairments, the authors found that the only difference between the two groups was that nighttime wakenings occurred more often in those with intellectually impairments (63.8%) compared to those without intellectual impairments (45.3%). Among the various age-groups in the study (younger than age 6, 6-11, and older than age 11), enuresis was reported more in the younger age-groups. Sleep is an important issue in the field of autism research as it has powerful adverse effects on individuals with ASDs. Another way that the neurobiology of ASDs can affect individuals on the spectrum is in terms of how they interact with others.

### *Socialization*

Regardless of whatever may cause it, autism is characterized by several impairments. As pointed out by the DSM-IV-TR (APA, 2000) and authors such as Cuccaro et al. (2003); Cuccaro et al. (2007); and Matson and LoVullo (2008), these impairments are largely in the ability to socialize and interact with others. These two areas, communication and social behaviour deficits, are affected enough to be considered two of the three major criteria for diagnosis of autism, as demonstrated in the DSM (APA, 2000). Nonverbal communication includes impairments in facial expression and body posture (Knickmeyer, Baron-Cohen, Raggatt, & Taylor, 2005). Individuals with ASDs also tend to have problems

socializing and meeting with new people (APA, 2000). Despite how serious these two areas are, this study focuses on a subset of the third category of diagnosis.

### *Repetitive Behaviours*

One area of interest is repetitive and stereotyped behaviours – the third category for diagnosis in the DSM (APA, 2000; Cuccaro et al, 2003; Matson & LoVullo, 2008). The repetitive behaviours are represented in several categories: stereotypies, fixations, and object attachments (Matson & LoVullo, 2008). South et al. (2005) point out that repetitive behaviours are classified under four categories according to the DSM-IV-TR (APA, 2000) and the International Classification of Diseases, 10<sup>th</sup> Ed (WHO, 1993); these categories include stereotyped motor mannerisms, object preoccupation, unusual patterns of interest, and insistence on sameness.

Stereotypies are motor behaviours that are repetitive and non-functional, that interfere with normal activities or cause self-injurious behaviour (SIB), and are distinct from tics and compulsions (APA, 2000). Nonharmful stereotypies include hand-flapping, body rocking, and shrugging of shoulders (Goldman et al., 2008). SIBs are more serious, as they can lead to physical handicaps, bodily injury, life-threatening damage, and even death. SIBs can also result in impaired physical, social, educational, and interpersonal skills; some examples of SIBs can include actions such as biting, head-banging, and striking oneself (Watchel et al., 2009). Other behavioural symptoms in Autistic Disorder, as defined by the DSM-IV-TR (APA, 2000) may include hyperactivity, short attention span, impulsivity, aggression, and issues with temper in younger children. One of the most prevalent sub-types of repetitive behaviours are circumscribed interests.

### *Autism and Circumscribed Interests*

CIs are unusual in several ways: the scope/degree of the intensity towards an

interest, what the interest is, both intensity and focus, and they appear to increase in intensity as time passes (Boyd et al., 2007; South et al., 2005). South et al. (2005) found that individuals with HFA had just as many – and in some instances, more – CIs as individuals with AS, regardless of how they measured CI engagement. The most significant problem with CIs is that they can interfere with a person's development and life, such as interfering with relationships (Mercier, Mottron, & Belleville, 2000). In the Mercier et al. (2000) study, which was one of the first in-depth qualitative studies to describe the phenomenon of CIs, none of the participants with an ASD were married, and all six varied in age between 19 and 52. Instead of pursuing social interaction, many of the individuals in Mercier et al.'s (2000) study preferred to focus on their interests because they provide a source of pleasure. While some positive aspects, such as relief and confidence, are noted by individuals with ASDs and their parents, parents are also concerned with repercussions on social life, as well as a general annoyance that comes with constantly referencing one's interests around individuals with typical development (Mercier et al., 2000).

According to Boyd et al. (2007), CIs have four attributes including: mass accumulation of information in regard to the person's preferred interests; difficulty focusing on other topics; duration of fascination; and intensity of the interest. Of concern is that, without intervention, these interests may not naturally develop into positive hobbies or skills (Mercier et al., 2000). Recent research has sought to determine if there are positive aspects to CIs so that they can be utilized for the benefit of persons with ASDs (Boyd et al., 2007; Winter-Messiers, 2007; Winter-Messiers et al., 2007). It does however behoove no one to place the perspective of the CIs solely on the individuals with those interests, as the parents and families of those individuals have unique insights into those interests as well.

*Families and Children with ASDs*

Families are the most important supports for individuals with ASDs, as they are not only the people who individuals with ASDs are most familiar with, their shared relations spur the entire social unit towards getting help. One of the most important areas of research in autism concerns the parents of these children. In the public image, autism is often seen as a terrible burden on families, sometimes with good reason: the individuals who are particularly affected and qualify as being low-functioning are the most severe cases of the syndrome and receive the most media attention and sympathy. These problems can be quite severe: referring to the DSM-IV-TR's (APA, 2000) core domains of autism (re: communication, socialization, and RRBs), problems can include a complete lack of language skills, withdrawal from socialization, and even the presence of SIBs. As caring for a child so profoundly impacted adds to the standard worries and concerns of being a parent, it has led to an increase in autism-advocacy by these parents. While most of this advocacy can be for the benefit of families with autism (e.g., government funding for reliable countermeasures, such as Intensive Behavioural Intervention and aid-workers), some choose to advocate for a cure for autism (as opposed to countering the comorbidities or addressing the most severe impacts of the syndrome) or redirecting their pain to perceived causes of autism, such as vaccines. Regardless of what aspect of advocacy these parents fight for, it is important to find out what areas are the most troublesome so that they can be addressed.

Parenting is not easy, even in the mainstream of populations of typical-developing children. While the impairments of individuals on the lower end of the autism spectrum make the situation of raising a child far more difficult, the impairments present in individuals on the higher end of the spectrum are nothing to ignore. Research has indicated

that CIs belong on the higher end of the autism spectrum in respect to other restricted, repetitive behaviours (Boyd, Conroy, Mancil, Nakao, & Alter, 2007). One can thus hypothesize that this would be an issue when present in a predominantly higher-functioning sample of individuals with ASDs, and that their parents would have a particular viewpoint that differs depending on the situation (i.e. SES, level of impairment, level of fascination). The author of this thesis therefore decided that it would be of greater interest to see how parents of children with ASDs (particularly high-functioning ASDs) would view the CIs of their child/children. The following are the summaries of several studies that have investigated the relationship between parents of children with ASDs and the CIs of their children.

Studies have found that autism is problematic for parents. In comparison of both Latin- and Anglo-American families that have children with other disabilities, mothers of children with autism in one study's sample had lower scores of well-being compared to mothers whose children had either cerebral palsy, Down syndrome, or only had intellectual disability with no other diagnosis (Blacher & McIntyre, 2006). Blacher and McIntyre (2006) found that mothers of children with autism scored higher on depression (mean ( $x$ ) = 13.9, standard deviation ( $sd$ ) = 8.9) – as measured by the Center for Epidemiologic Studies - Depression (CES-D) – as compared to mothers whose children had cerebral palsy ( $x$  = 12.6,  $sd$  = 10) and Down syndrome ( $x$  = 10.2,  $sd$  = 7.9). Only those mothers whose toddlers had intellectual disabilities only ( $x$  = 15.5,  $sd$  = 12.6) scored higher on depression than the mothers of toddlers with ASDs. The mothers whose children had ASDs also had higher scores of negative impact than the other three groups, as measured by the Family Impact Questionnaire (FIQ) ( $x$  = 28.9,  $sd$  = 9); scored lowest on both morale, as measured by the Philadelphia Geriatric Center Morale Scale (PGC) ( $x$  = 10.4,  $sd$  = 4.2); and also scored the

lowest on positive impact, also measured by the FIQ ( $x = 13.3$ ,  $sd = 6.1$ ), compared to the other three groups.

It has been documented that raising a child with an ASD can also be stressful (Davis & Carter, 2008). Davis and Carter (2008) attest that while most studies previously measured the stress in parents of older children with ASDs (generally of preschool-age or older), few had previously measured the stress in parents of children with ASDs who were toddlers. The authors conducted a study on child behaviour and parental stress of mothers and fathers of 54 toddlers, with a mean ( $x$ ) age of 26.9 months. Their results corroborated the work of previous studies: both mothers and fathers of toddlers with ASDs reported higher stress, as measured by the Parenting Stress Index (PSI) (mothers:  $x = 83.8$ ,  $sd = 22.6$ ; fathers:  $x = 79.6$ ,  $sd = 19.3$ ). While parents shared similar levels of stress, they reported higher stress especially when evaluated in regards to overall parenting stress, parent-child relationships, and distress in parents, all a response to deficits and delays in their child(s) socializing. Mothers were more affected by problems with their offsprings' ability to regulate their behaviours as opposed to the fathers, possibly due to mothers generally having higher involvement with their children on a daily basis, scoring higher on measures of stress, depression, and anxiety. For the fathers in the Davis and Carter (2008) study, problems with externalizing behaviours had the greatest associations with stress, aside from problems with core autism behaviours (re: deficits in communication, deficits in socialization, and the presence of RRBs).

Siblings of children with autism have also been found to be more negatively affected. They tend to be more poorly adjusted, have poor social competence, and have higher rates of depression (Macks & Reeve, 2007). In those children who had a sibling with a disability, their mothers rated them as having higher rates of aggression, depression,

and overall pathology compared to self-reports by those children.

Some of the stress related to caring for a child with an ASD can stem from one of autism's core diagnostic problems: social hindrance (Rutgers et al., 2007). In particular, Rutgers et al. (2007) looked at attachment between parent and child as a result of the social impairments stemming from ASDs that may therefore affect the quality of the parenting. Rutgers et al. (2007) point to a meta-analysis by Rutgers, Bakermans-Kranenburg, van IJzendoorn, and van Berckelaer-Onnes (2004), which demonstrated that children with ASDs were significantly less securely attached to their parents than children who did not have ASDs. While children with ASDs are able to form secure attachments with their parents, this relationship was strained because of social impairments (Rutgers et al., 2004). The Rutgers et al. (2007) study examined 89 families of individuals with ASDs, learning disabilities, mental retardation, and controls, and assessed their parenting style, parental efficacy, parental experiences of daily hassles, social support, and psychological problems. The control-group parents more often utilized authoritative parenting styles and received less social support. The children with ASDs were less secure than their cohorts, but their parents perceived themselves as being healthy and balanced; they also had more social supports.

Another study was inspired to investigate stress and negative impacts for parents raising children with ASDs. Smith, Seltzer, Tager-Flusberg, Greenberg, and Carter (2008) compared the coping strategies employed by the mothers of toddlers with ASDs to mothers whose toddlers had other developmental disabilities (DDs) such as Down syndrome, Fragile X syndrome, and cerebral palsy. 153 mothers of toddlers with ASDs and 201 mothers of adolescents with ASDs participated. The authors found that, despite significant amounts of distress in both sets of mothers, the mothers of toddlers used less emotion-



focused coping strategies and more problem-focused coping strategies. Emotion-focused coping strategies are those that attempt to deal with the feelings and perceptions of distress, such as denying the level of stressors. In comparison, problem-focused coping strategies are those that attempt to change the stressors and solve the problem being posed. The use of more problem-focused coping strategies and less emotion-focused coping strategies was also found to be generally associated with better well-being in the mothers who did so, regardless of the specific condition their children had. The mothers of adolescents with ASDs used more emotion-focused coping strategies, such as behavioural disengagement.

The role of parenting has changed in recent decades, and this may reflect why some have found that mothers of children with ASDs are more affected by mental health issues than the fathers (Herring et al., 2006). Other studies have found mixed results: while traditionally mothers have been found to be the ones reporting higher levels of stress – perhaps due to their historical role as the childcare providers, more recent studies show comparable levels of stress in mothers and fathers (Davis & Carter, 2008). Some of the things that can contribute to these stresses may include what parents have to do to accommodate their children. Attwood (2003; 2007) points to the works of Bashe and Kirby to demonstrate examples of accommodations parents have to make for their children's interests. Such accommodations include: making special trips to replace/purchase item related to interest; deliberate avoidance of places for fear that interest will be engaged or reinforced; tardiness for scheduled events such as appointments, work, or school; take specific routes while driving to accommodate interest; special vacations related to interest; numerous trips to places or events most people would be satisfied to experience once or twice in a lifetime; and departing from social situations because accommodation attempts failed (Bashe & Kirby, 2010). Without taking measures to stem the control of the CI over

the child, parents can find themselves having to go to exhaustive lengths to satiate the desires of their children.

### *Repetitive Behaviours and Circumscribed Interests*

One question that has been pondered in the literature is whether there is a difference in CI intensity between individuals with different diagnoses. While not all individuals with ASDs have CIs, the majority do: Klin et al (2007) found that 75% of preschool students and 88.5% of elementary school students with ASDs had CIs, with the bulk of the CIs stemming from a memorization of facts in both groups. Regarding the broader category of RRB's – of which CIs are a part of – it has been pointed out that RRBs have been demonstrated in individuals with diagnoses other than ASD, including Parkinson's, schizophrenia (a diagnosis that was once often confused with autism), and Fragile X syndrome (Carcani-Rathwell et al., 2006). Carcani-Rathwell et al. (2006) found that while restricted behaviours are more common in individuals with PDDs, their data did not fully support the idea of “lower-order” behaviours, such as stereotypies, being associated with individuals with lower levels of development, nor “higher-order” behaviours (such as CIs, routine rigidity, and resistance to change) being more associated with less cognitive impairment; rather, both the “lower-” and “higher-order behaviours” seemed to consistently occur together in individuals with PDDs, in both individuals with intellectual impairment and those without intellectual impairment. Other studies have supported the idea that these restricted behaviours have no significant differences between diagnoses on the autism spectrum: Cuccaro et al. (2007) found no such differences regarding individuals with high-functioning autism and Asperger's syndrome; Papageorgiou et al. (2008) replicated said findings in their native Greece, and came to similar conclusions; South et al. (2005) found no support for the idea that CIs are more apparent in HFA compared to AS – by contrast,

they found that they were quite similar in terms of frequency, intensity, duration, and the interference of interests.

One statement that could easily describe the phenomenon of circumscribed interests is that they are diverse and are specific to the individual. There are no set rules defining how to codify or categorize CIs, but a general theme that runs through many studies is that they can be on practically any topic, ranging from the mundane to the unusual (see Klin et al., 2007). The categories vary depending on the authors, with few authors describing or labelling the same category. Attwood (2007) defines these categories as 1) collections and 2) acquisition of knowledge on a specific topic or concept. Collections, something that Attwood (2007) points out that even Asperger, in his 1944 paper, noted, are present in children and adults with AS, and can include the collection of matchboxes (Asperger, 1944; Attwood, 2007), old telephones (Attwood, 2007), and records. Attwood (2007) also notes that with the accumulation of these objects, there is a desire to find symmetry and harmony by sorting them. The acquisition of knowledge, which can stem from collecting objects, allows the individual to become an expert in the CI (a topic that Asperger was aware of, dubbing his participants, "Little Professors"). The result can be an encyclopedic knowledge of facts on various topics. One area of expertise that seemed to be recurring at Asperger's clinic from the 1950s to the 1980s was an interest in animals and nature - with technical and scientific interests being the second most popular, and the third being public transportation (Attwood, 2007).

Attwood (2007) notes that a modern study of the parents of children with AS confirms Asperger's themes (with the exception of themes that have developed or become popular in the West since Asperger's passing) including computer games, science-fiction, and anime. Attwood (2007) also notes that minor gender differences have been observed,

the biggest differences being that girls with AS may have interests in collections that are typical in most girls, and that some have tended to develop interests in acquiring fiction-related facts rather than facts in real life (i.e., acquiring knowledge from Shakespeare or J.K. Rowling as opposed to facts); by contrast, males tend to accrue facts pertaining to real-world topics.

Different authors have identified different categories based on what CIs were reported in their studies. Winter-Messiers (2007) found eight common themes in the interests presented in her study, including transportation, music, animals, sports, video games, motion pictures, woodworking, and art, with CIs including cars, frogs, role-playing games, Star Wars, anime, and vampire movies. Mercier et al. (2000) described collections, music, and knowledge/activities pertaining to very precise areas (which are similar to Attwood's (2007) categories); some identified CIs include collecting books and videos, repetitive playing of music, sports statistics, computers, erotic phone conversations, and the American Revolution. While Klin et al. (2007) did not have a specific list of categories for their observed interests, they did create categories for coding purposes.

One of the biggest areas of concern with CIs involves the kind of effect they may have on an individual. Such concerns may be due in part to the public perception of autism as largely negative, but it was not until Mercier et al.'s (2000) study that the idea that CIs are more than just hindrances emerged. There are researchers on this topic today (e.g., Boyd et al., 2007; Mercier et al., 2000; Winter-Messiers, 2007; Winter-Messiers et al., 2007) who have stated that there are positive aspects to CIs that should not be ignored. Despite this new line of research, there are still studies that focus on the negative aspects of CIs, while others focus on both positive and negative consequences. While this focus on the negative is understandable, it does not help advance research on CIs, nor does it help

advance ways to reinforce positive aspects of CIs. It therefore becomes necessary to consider both the positive and negative aspects of CIs critically, and not just give in to archaic prejudices of aesthetics and comfort on the part of the parents.

*Aspects seen as less positive*

South et al. (2005) demonstrated that CIs are not an impairment that decreases with age, unlike other measures of restricted and repetitive behaviours, and may become more apparent due to improvements in other abilities, such as socializing and communicating. One of the earliest hindrances to individuals with ASDs was not necessarily their own interests, but rather the perceptions of others toward those interests (Mercier et al., 2000). Mercier et al. (2000) found that half the participants in their study did understand that their family members were burdened by their devotion to their interests, noting that they found them annoying, unoriginal (the individuals seldom discussed other topics), and potentially harmful (one individual incurred debt in the pursuit of his/her CI).

One of the most unfortunate drawbacks of CIs is their intensity. This intensity can interfere with learning in students, namely self-motivated learning (Klin et al., 2007). Klin et al. (2007) also found that this interference was minimal in their preschool-age sample, but significant in their elementary-age sample. This intensity can also leave individuals with ASDs in a position that conflicts with not just established social customs and rules, but also established legal practices and laws. It should be noted that this in no way implies that people with ASDs are criminals or flagrantly disregard law and order – in fact, the rates of crime commission are about the same between the population of individuals with Asperger's and with the typically-developed population (Attwood, 2007). This importance is further demonstrated by information from the literature amassed by Woodbury-Smith et al. (2010), who point out that other studies have found different results. Woodbury-Smith et

al. (2010) also noted that the connection between CIs and criminal behaviour is poorly understood: one postulate explaining this relationship is a direct connection between CIs and criminality, whereas another idea is that it is the intensity of the individual's fascination that is causing the problem.

Woodbury-Smith et al. (2010) investigated individuals with ASDs who were either offenders or not offenders and hypothesized that the offenders would have CIs that were more violent than the non-offenders. None of the non-offenders had a violent interest and only four (19%) of the offenders had an interest related to something violent (e.g., fire, weapons, and World War II), with only three having a relation between their CI and their offence (e.g., arson, fraud). While offenders with ASD were more likely than non-offenders with ASD to have a violent CI, the majority of the offenders did not have a CI that was related to violence.

#### *Positive aspects of circumscribed interests*

In the past two decades, the perspective on CIs has begun to change. Originally viewed as distractions, disruptions, nuisances, and in other negative lights, it is now becoming more accepted that CIs are an important part of the individual with ASD's life (Boyd et al., 2007; Winter-Messiers, 2007). As previously discussed, while legitimate criticisms still exist – such as hindering socialization or interfering with chores – these are side-effects that can be mitigated and do not present a major source of conflict.

One of the most important aspects of CIs, at least to the person with ASD, is that they are a source of pleasure. Circumscribed interests are, after all, things that are interesting to the individual in particular. The fascination would thus naturally be a source of pleasure or comfort for that person. Contrary to earlier research, it is becoming more obvious that their interests are not always a source of conflict (Mercier et al., 2000):

parents describe CIs as sources of pleasure, with restful and calming effects, with some viewing them as educational, a source of expertise, and even a prevention of felonious behaviour (Mercier et al., 2000).

Perhaps one of the most promising new areas of research is in using CIs as motivators, particularly to overcome problems. One particular challenge for individuals with autism is the aspect of socializing with others; it is one of the defining features of autism (APA, 2000). CIs could be used to motivate children with ASDs to pursue relationships with others who have similar interests; whether those other children also have ASDs or not is irrelevant. Boyd et al. (2007) put this idea into practice in their study. They found that children with ASDs would normally select an object that represented their CI a majority of the time compared to less preferred objects; they also found that those same individuals would also spend a majority of time with the peer with his/her preferred CI. The presence of the CI helped initiate the majority of the social interactions.

Winter-Messiers et al. (2007) performed a strength-based model for individuals with AS, using individuals' CIs to motivate them in several areas of focus, one of these being in social and communication deficits. In all of their areas of deficit, which include social/communication deficits, as well as emotional, sensory, fine-motor, and executive-functioning deficits, they improved when their CIs were utilized. For children whose interests were used to stimulate social skills, they found that reluctance to speak became inhibited as those interests spurred the individuals to engage in conversations, used more appropriate social skills, such as nonverbal language, and were more positive and exuberant. Winter-Messiers (2007) found similar results, with children with AS becoming ecstatic about participating in her study when their CIs were brought up. The exception was that they were also reluctant to bring them up or express them, especially to school peers,

fearing being ostracized and rejected. Corroborating Winter-Messiers et al. (2007), they also found that CIs could overcome communicative deficits. Others, such as Klin et al. (2007) found that interaction with family members, peers, and other adults was stable when their CIs were based on visual memory, verbal memory, and letters/numbers. The inclusion of CIs into communicating with individuals with ASDs offers a greater chance of not only reciprocation by the individuals with ASDs, but also eliciting their enthusiasm, passion, and attention, and the utilization of these interests should be undertaken.

### *Purpose*

The purpose of this Master's thesis was to evaluate how CIs affect the lives of individuals with ASDs. The primary research question was, “How do circumscribed interests, when present, play a part in an individual with ASD's social and familial lives.” A second research question was “how do CIs affect an individual's performance on scholastic, household, and other duties?” The author was also interested in the degree to which the interests affected the individual's life on a daily basis and how the interests were perceived differently between parent and offspring. While originally the author was interested in looking for positive aspects, it was decided to keep the questions about benefits/detriments neutral so that both negative and positive aspects could be described by participants freely.

For the purpose of this study, CIs were documented using qualitative methods, namely a phenomenological perspective. A phenomenological approach allows for several effects: an understanding of cultural and social patterns of belief about CIs, and how people, with and without an ASD, interpret CIs (Rothe, 2000). Phenomenology also allows for further critical analysis, and helps uncover meaning that individuals, both with and without an ASD, attach to CIs (Rothe, 2000). With the assistance of 11 families, interviews were conducted to determine how people perceive CIs when they themselves have an ASD. The



interviews gave a more detailed analysis of the experience of having CIs and more detail in regards to the specific CI(s). A perspective of someone close to the individual was sought, but from someone who is detached from the CI(s) to gain more unbiased and adult-oriented perspectives and beliefs.

### *Statement of Problem*

The academic literature has been scant on the topic of CIs (Mercier et al., 2000; Winter-Messiers, 2007). It has only been in the past decade or so that interest in the area has begun to peak, and even then most studies note the same problem: not enough research exists on the topic of CIs. It is worth noting that there is not even a consensus on what to call these intense interests. Winter-Messiers (2007) points out that different authors have called these interests by different names, although they all seem to use wording that describes the same phenomenon. In the research conducted so far, special interest areas (SIAs) and circumscribed interests (CIs) were the most popular, and the author has decided to use the term CI.

Previous studies have looked at a wider array of demographics in their studies of CIs, from specifically individuals with AS, to a younger or older age group as the sample, to smaller sample sizes in an effort to describe specific stories in greater detail versus larger sample sizes to describe more effects (e.g., Mercier et al., 2000). For the purpose of the present study, these issues were attempted to be balanced, as it would be beneficial to have as many participants as possible, but not at the expense of the depth and detail of the description that the participants could regale about their lives. In an effort to achieve a larger sample size, an age range of young child to young adult (early 20s) was maintained – with the one exception of an individual with AS who was 30 at the time of the interview.

Finally, most of the studies prior to the last few years seem to view CIs in a negative

context. While there are certainly situations where fascination with topics unrelated to duties (i.e., schoolwork, studying, employment, household chores) would impair those duties if left unchecked, a tendency to view the CIs as inherently negative has skewed past studies in favour of corroborating this viewpoint (Winter-Messiers, 2007; Winter-Messiers et al., 2007). However, in the last few years, the realization that CIs are integral to the life of an individual with ASD (Mercier et al., 2007; Winter-Messiers, 2007) has helped inspire studies that look for positive impacts of CIs and potential ways in which to harness them to focus the individual on the task at hand. This focusing of the CIs would thus assist in the “normalization” of many key areas of life, such as social interaction and communication skills.

### *Rationale*

Though autism has been researched since the 1940s, it was not until the late 20<sup>th</sup> century that the concept of CIs began to receive serious attention (Klin et al., 2007; Mercier et al., 2000). These interests demonstrate an astounding fascination with a particular topic (or topics) and can vary in intensity and in terms of the topic(s) of interest. In some cases, CIs can lead to career interests (Winter-Messiers, 2007); on the other hand, many parents of children with autism see CIs as a hindrance, with many laypeople and professionals in the past few decades describing CIs as addictions or obsessions (Mercier et al., 2000; Winter-Messiers, 2007).

Along with research done on CIs in the past, such as Hans Asperger's and Leo Kanner's respective studies in the field, Klin et al. (2007) elaborated that there was little research on CIs in the years following Kanner's and Asperger's works. Besides Kanner's and Asperger's most influential studies, Robinson and Vitale (1954) performed an original study investigating the CIs of children (Klin et al., 2007; Robinson & Vitale, 1954). Klin et

al. (2007) point out that aside from Kanner publishing academic commentary on Robinson and Vitale's (1954) paper, there would be no empirical work on CIs until Baron-Cohen and Wheelwright (1999), almost half a century later. Mercier et al. (2000) point out a similar view, that only a handful of studies on restricted interests were performed prior to their own paper. Only a few studies had used qualitative techniques to study high-functioning autism, with case studies, discourse analysis, and in-depth interviews being greatly underused (Mercier et al, 2000). Furthermore, to the author's knowledge, much of the research that has been done on the perception of CIs has been neglectful of the individuals with ASDs themselves; in recent years, as the issue has gained prevalence, there has been more research investigating the individuals themselves (i.e. Mercier et al., 2000; Winter-Messiers, 2007).

More studies, however, have focused on the perception of CIs by people close to the individuals, such as family members, teachers, and friends (Mercier et al., 2000; Klin et al., 2007; Winter-Messiers, 2007; Winter-Messiers et al., 2007). These perceptions can be positive or negative, but the research literature has in the past focused more on negative effects, creating a small gap for more studies with perceptions that are more positive towards CIs. These interests have the potential to be a hindrance or a benefit to individuals with ASDs, and if properly motivated, could potentially serve great benefits to the next generation; even the knowledge gained via an expansion of this research could have drastically positive benefits for the current generation, in terms of assisting individuals who are typically-developed and individuals with autism in cooperating for a better future.

### *Reflexivity*

An important procedure in qualitative research is reflexivity. Reflexivity is a critical practice to social research (Adkins, 2002), and is considered a powerful methodological

and analytical tool (Haney, 2002). The following are issues that may influence this study, which range from possible confounds or conflicts of interest to minor issues such as shared diagnoses with the author.

From a personal standpoint, I have had little contact with ASDs prior to the commencement of this study. In contrast, however, what few experiences I have had have been surprisingly strong. First, I have a younger cousin who has severe impairments due to a combination of autism and cerebral palsy; as such, he is incapable of walking without assistance, is incapable of spoken language, and demonstrates both restricted and repetitive behaviours (such as teeth grinding) and the occasional self-injurious behaviour (head-banging); when he was younger he would also bite people when agitated. I recall one vivid experience when he was about six or seven when he bit me on the side of the face because he was getting too excited. With him being the new baby of the family, and being one of the few members of my extended family younger than I in the community, he and I formed a close bond that persists to this day.

Secondly, a former professor of mine has a son with AS. Remarking on this the first day we met, and his own quirky teaching style helped me bond with him, and I still see him as a valuable mentor. Interacting with him and his son were the first real experiences I had with a family affected by autism that I was not related to.

Finally, the most important issue is to elaborate on my own Asperger's Syndrome. I received the diagnosis in Grade 11, but did not think much of it until I was in my third year of undergraduate education, when I was thinking about what to do with my Bachelor's thesis and my post-graduate choices. Upon further learning – especially how the diagnosis matched me perfectly, even right down to the CIs – I embraced the label. Admittedly, the drawbacks can be disabling: my own CIs sometimes distract me from duties, such as

chores, work, and schoolwork; occasional depression and panic issues can be triggered by suggestions that – to me – seem more serious than they actually are. I also have a minor deficit of social skills and lower desire to meet new people compared to individuals who are not developmentally different that has impacted my social life, albeit not as negatively as one might expect. Despite these drawbacks, I have come to see that I am who I am, and without my AS I would be – in my opinion – a boring person. As such, removing AS from me would be removing a part of my personality, several of my most cherished functions (e.g., intelligence), and thus deprive me of myself. In the face of the [seemingly] growing anti-science movement that views autism as a disease, curse, death sentence, or major tragedy, I have embraced a staunch sense of pride of having AS and view the advantages our people bring to society to be too important to let us be degraded by well-meaning – but ignorant – parents. To me, taking us back to the days of institutionalization or eugenics would be the worst possible scenario.

My own perspectives on CIs are that they are a very interesting phenomenon. In my own case, I am so fascinated by Japanese animation – in particular shows involving large, pilot-able robots – that I know the model numbers of many of these fictional weapons of war. As such, I have a strong viewpoint that CIs are beneficial, but only when they can be properly utilized to motivate the individual. The research would indicate that this would be easier than would be thought, and since autism is a lifelong diagnosis, the people with the particular syndrome or disorder will not merely fade away, they will take up various seats in society, from cashier at Tim Horton's, to university professor, to construction worker, to politician, to computer expert; many will fill numerous roles in society, including parent, voter, patient, taxpayer, and inevitably, retired citizen. Many areas of our society – especially long-term care, medicine, social services, and other jobs that require engaging

with people directly – will be required to have a better understanding of autism and CIs, as well as having even rudimentary skills in being able to motivate and/or calm down an individual with an ASD.

Reconciling my own perspectives on CIs with my position as an interviewer has not been as difficult as I would have expected, but it is also not an easy one. I admit that when I went in to each interview, I hoped that the individuals with ASDs themselves would have an interest similar to one of my own. In terms of subjects that I was particularly fascinated with at this stage of my life, only one participant mentioned having more than one interest that we shared. In that sense, it helped make it easier to go through the interviews, as well as the follow-up processes. There was something with which I could identify this person, not just a label, but a passion. Several other of the individuals who had CIs had interests that I had shared at their age (e.g., Yu-Gi-Oh! Trading card game, dinosaurs, animals), but there were also a few that were not of any interest to me at all (e.g., airplanes, shoes, weather). Nonetheless, I found that, in the follow-up stages, while there were interviews I had slight preference toward, this was not related to CIs or the families themselves. Retroactive preference for specific interviews was based on how well the interviews were conducted, if participants cooperated, and if sufficient details were extracted.

Despite these issues, I was amazed by how easy it was for me to remain as “neutral” as possible in data collection, transcription, and analysis. It is of course impossible for any researcher to be completely free of bias, but it is important for a qualitative researcher to restrain one's beliefs and opinions as much as possible so as not to contaminate the data. I had feared that biases might have surfaced, which could have affected the outcomes of the data collected, but I do not think this was the case. My main issue of concern was more of a struggle or an urge, but that did not occur at all.

Other issues emerged during the course of the interviews that I had to keep mindful of and remain neutral and objective. One participant, who identified a strong fondness for weather, was surprisingly a climate change denier, something I would have not expected. I did press for emphasis, but did not feel it necessary to push the notion of the overwhelming scientific consensus on the subject for fear it would steer away from relevant conversation and perhaps influence the participant to withdraw.

I had interviewed a mother who runs a local support group, whom I knew was under the opinion that all three of her children had developed autism from something she had done during pregnancy or post-natal care (i.e., Vaccines), and this was around the time that the original fraudulent study linking the MMR vaccine to autism was retracted; I decided not to push the issue since that was concerned with the causes of autism and not the CIs. Finally, I was surprised by how well I was able to see the people who participated in my study as people first, and individuals with a specific diagnosis second. Regardless of whether it was the presence of a quirky feature or an annoying one, I was able to overcome my social anxieties about going to strangers' houses, my dislike for annoying or uncooperative behaviour, and my preference for like-minded individuals. Simultaneously, I was surrounded by fellow human beings and brethren with a different lot in life.

A final issue of note in this regard was in respect to one participant who had a fondness for the Yu-Gi-Oh! Card game. Being a former fan myself, and one who drifts in and out of the phenomenon every few years, I confess meeting this participant inspired in me an urge to update myself with the game and bought some new cards only a month or so after the interview. I even played a few rounds with that participant a few months later. I had viewed this as a possible confound in the finishing stages of this study, but this does not appear to be the case, though I still feel it is important to stipulate for an audit-trail.

The next chapter of this thesis is my methods. In that chapter, I will detail the processes used, describe the families interviewed, and other information as necessary. Such information includes what was found in the data, descriptions of the interests and situations of the participants.



## Chapter 2: Methods Section

This chapter describes the methods used in this thesis. Laid out in detail are the theoretical underpinnings – what background of qualitative research was used to approach the study, the specific methodical processes, including the conducting of interviews; the descriptions of the participants: the chapter concludes with the ethical issues surrounding the study and how they were addressed.

### *Theoretical Underpinning*

Any qualitative study requires a framework, an idea around which to structure the thesis. A phenomenological approach was selected because of its inquisitive nature; phenomenology seeks to understand why a phenomenon is occurring (Rothe, 2000). Phenomenology is a non-causal method (i.e., a method that does not create a reality, but recreates it or discovers it in the investigation) used to enhance the understanding and discovery of a person's experiences or their shared experiences with others. It focuses on how an individual orients himself/herself to the surrounding world, and how that individual creates his/her own reality, each one unique to each person (Parse, 2001; Rothe, 2000). Phenomenology reconstructs and discovers the participant's reality by focusing not just on what the participant says, but on how he/she says it (Rothe, 2000). This study also benefits from understanding and detecting not just verbal but nonverbal responses, such as body posture, facial expressions, and vocal tones.

Phenomenology was perceived as the most appropriate framework for this thesis. The primary reason was on the basis that it attempts to find out about a particular social phenomenon, in this case the perceptions of the CIs of individuals with ASDs by themselves and their parents; phenomenology also would help ascertain how the CIs affect (and are perceived to affect) the lives of both the individual and their families. Another

qualitative method, known as symbolic interactionism, was considered due to similarities between the two methods, such as that both methods attempt to understand meaning (Rothe, 2000). Phenomenology was chosen as the better model for two reasons: because symbolic interactionism does not rely on finding nonverbal cues in the interview process (Rothe, 2000); and also because symbolic interactionism focuses on the social construction of the phenomenon and only certain aspects of the phenomenon whose interpretation is subjective.

### *Methods*

As this study was of a qualitative nature, data was collected primarily through semi-structured interview sessions (refer to Appendix A for the interview guide). Unlike purely structured interviews, other questions could be asked during semi-structured interviews in response to novel ideas expressed by the participants, and pre-written questions can be expanded on based on the dialogue from the participant(s) (Whiting, 2008). Other advantages of semi-structured interviews are that they are more personal and open than structured interviews, they gather detailed narratives, and can range from a short interview session of about 30 minutes to long sessions that last several hours. For the purpose of this study, it was decided to let the interviews flow naturally and not be confined by time. Most interviews lasted from 30 minutes to an hour with parents and 15 to 30 minutes with young children. Instead of forcing the parents to discuss irrelevant issues just to meet a time quota, the interviews were kept brief but informative until the required amount of information was acquired. In the case of individuals with ASDs themselves, most of them were legal minors and it was difficult to hold their attention for very long. The use of force or coercion on the part of the author to encourage the participants to stay when they did not want to, or due to the nature of their ASD, would have been unethical and impractical.

The interview format was comprised of a series of predetermined questions specific

to the individual being interviewed (i.e., individual(s) with autism, the parents of children with ASDs) (Please refer to Appendix A). Questions were similar in nature: a question such as “How do you think the CI affects schooling?” merely needed to be rephrased depending on who was being asked; others, such as “How does the CI interact with you and your family's social lives?” were deemed to be unsuitable for the individuals with ASDs due to a notable deprivation of theory of mind (refer to Baron-Cohen, Leslie, & Frith, 1985). Questions were related to individuals with specific ASDs and their interests, as well as how those interests affected the social, academic, and familial aspects of their lives.

The interviews were digitally recorded for reference during data compilation and data analysis; these recordings are slated for deletion following completion of the research, and is covered in more detail in the ethics section of this chapter. Interviews were conducted in locations mutually agreed upon by both the author and the parent that served as liaison for that family. Only two interviews took place at locations other than the participants' homes.

Interviews were originally intended to be conducted separately because the individual with the ASD would feel inhibited by the presence of his/her parent(s). However, the use of interviews with both parents and individuals with ASD communicating at the same time was interesting as the individuals provided unique viewpoints and conflicts that could be observed. Such a scenario was enacted only twice, both times at the request of the parents. The author did not insist on one-on-one interviews in these cases, positing that the participants might feel more at ease in a group setting. In the majority of the interviews, the parents were present with their children during their interviews, with only one family opting to let their children speak alone. In a few instances, the children were present when their parents were interviewed, but did not participate.

### *Participants*

The purpose of this study was to gain the perspective of individuals with ASDs and their parents in regard to CIs and frame them within a phenomenological perspective. Individuals with ASDs were chosen as participants because of the focus of this study: their stories and perspectives would be more intimate and knowledgeable about CIs than those of their parents who were not interested or knowledgeable in the topic area. The individuals with ASDs were also able to offer first-hand information on the effects their fascinations had on other areas of their lives, and their perspectives served to balance their parents' perspectives. This balancing was to minimize bias, as an individual with ASD may not be able to see associated and potential problems with the particular CI of interest, and a parent may not be able to see the specific qualities that intrigue their children. By using multiple sources, inherent and unavoidable views – particularly those from a personal point of view – from a single source is lessened.

Because of issues of emotional investment and the dispositions from individuals with ASDs toward their CIs, as well as, in the case of younger children, a lack of knowledge regarding their social situations or even their own conditions, another source of information was necessary. Parents made an excellent choice for participants; they served to offer an insight into the CIs that was not as emotionally attached as in their children. None of the parents in this study had a diagnosis of an ASD, though one father admitted that he may be a high-functioning individual with autism or Asperger's as he shares many of the “tics,” socialization drawbacks, and fascinations with particular topics.

Participants in this study were initially recruited from local agencies in Northern Ontario. Participants were directed to the author by the agencies, and most of them agreed to become participants through e-mail correspondence. Other participants were recruited

via recruitment posters (see Appendices B & C). Participants were grouped into family units, with at least one child with an ASD being the subject of the interview and at least one parent giving an interview. Grouping participants, data collection, and pseudonym application were made easier by the application of grouping by familial association.

Most families had only one offspring with an ASD ( $N=7$ ), while three families had two children with ASDs, and another family had three children. A total of 11 families were interviewed, with a mother participating in every interview, a father participating in three of the interviews, and a grandparent in one interview. In total,  $N=33$  people were participants in the study (16 parents and 17 individuals with ASDs), with  $N=28$  people directly participating and an additional five children represented by their mothers because of either inability or unwillingness to participate in interviews.

Participants were mostly residents of Northern Ontario within a middle-class socio-economic status. Individuals with ASDs had an approximate median age of 9 years, with two individuals over the age of majority. There was a tendency for the children to be higher-functioning or less severely affected by autism ( $N=11$ ); two girls had PDDs; one young adult male had a diagnosis of PDD-NOS; one young male had a diagnosis of mild to moderate autism; another young boy had a diagnosis of mild autism; five males had a diagnosis of Asperger's; and one young male had a diagnosis of "Communicative Autism." In terms of gender, most of the participants with ASDs were male ( $N=13$ ), and most of the parents were females ( $N=11$ ). The following diagram, Table 2, is a list of the participants who involved in this study, grouped by family unit, and identifying appropriate demographic information, such as gender and specific diagnosed PDD.

*Table 2: Participants*

<b>Family #</b>	<b>Name of Parent</b>	<b>Gender</b>	<b>Name of Child</b>	<b>Gender</b>	<b>Diagnosis</b>
1	Kathy Aker	Female	Graham Aker	Male	AS
			Lyle Aker	Male	Moderate Autism
2	Denis Jackson	Male	Travis Jackson	Male	AS
	Taylor Jackson	Female			
3	Betty McDiarmid	Female	Patrick McDiarmid	Male	AS
			Liam McDiarmid	Male	Mild-Moderate Autism
4	Maria Britannia	Female	Larry Britannia	Male	High-functioning
			Calvin Britannia	Male	Low-functioning
			Euphie Britannia	Female	High-functioning
5	Emma Bidan	Female	Charles Bidan	Male	PDD-NOS
6	Beverly Archer	Female	Jake Archer	Male	“Communicative Autism”
	Scott Archer	Male			
7	Rachelle O'Neill	Female	Leonard O'Neill	Male	AS
8	Laurie Sweeney	Female	Walter Sweeney	Male	AS
9	Melinda Testarossa	Female	Kyla Testarossa	Female	PDD
			Tammy Testarossa	Female	PDD
10	Victoria Helsing	Female	Billy Helsing	Male	AS
	Richard Helsing	Male			
11	Leah Lewis	Female	Jason Lewis	Male	Mild Autism
	Hans Lewis	Male			
	William Rogen	Male	*Leah's Father		

### *Families*

The first family were the Akers. The interview with the mother, Kathy, took place at a local coffee shop to discuss her two boys, Graham (6) and Lyle (4). Graham was diagnosed with Asperger's and had a CI for frogs. Lyle was diagnosed with a mild impairment of autism, and had a CI for female shoes, specifically with stiletto heels.

The second family were the Jacksons. The father, Denis, is an academic, and the mother, Taylor, is a language instructor. Their son, Travis, was 8 years old at the time of the interview. Both parents were interviewed at home at the same time before proceeding to Travis. Travis has a diagnosis of Asperger's syndrome and has a particular fascination for planes – especially plane crashes. Since the initial interview, it has been learned that he has now shifted back to a preference for cars. While Travis was at one time interested in cars prior to his plane fascination, his new interest is much stronger, including the ability to almost correctly name the make, model, and year of a car just by observing it. He also invades people's personal space to ask them directly what kind of vehicle they drive, even if they have only just met him. Denis also stipulated that his son's interests change over time, but that plane crashes had lasted the longest.

The McDiarmid family was the third family interviewed, also at their home. The mother, Betty, took part in the first interview, and her children were interviewed separately. Betty described her children's love of Thomas the Tank Engine in their youth, and currently for an alternating love of Sonic the Hedgehog and Mario. Her eldest son, Patrick (13) followed her, and denied having Asperger's or any other form of autism. He was convinced that he was over it and did not fully corroborate all that his mother had said. Patrick, despite rebutting his condition, was still bullied at school and he could not understand why. While he did admit to having an interest – however minutely – in Sonic the Hedgehog, he

claimed that his younger sibling was more interested in the video game franchise. His brother, Liam (11), had a more severe diagnosis of autism at a younger age, but had been re-evaluated years prior and deemed to be less affected than originally suspected. He corroborated his mother's confirmation of a CI in Sonic, and would describe him in much detail – so much so that the author, despite playing the franchise as a child and teenager, was forced to utilize a Sonic the Hedgehog Wikia for additional information.

The fourth family was the Britannia family. The mother, Maria, is a medical practitioner and has three children. Euphie (12) has a CI in drawing, and Larry (11), who was also interested in drawing, but was also interested in building and modelling with clay. The youngest son, Calvin (8), was lower-functioning and would not have been able to participate in the study due to language delay. He had a CI with singing, and a specific fascination for singing from Disney movies.

The fifth family was the Bidan Family. Emma Bidan, a civil servant, is the step-mother of Charles, who has a diagnosis of PDD-NOS and is older than previous participants (22 years old). Charles had a strong CI for the weather – specifically meteorology, as well as extremely violent storms (lightning storms, blizzards, and tornadoes in particular – and had strong, but lesser interests in architecture and medical technologies). Although he has a lower IQ than most of the other participants, Charles lives alone during the work week and is able to provide for himself despite being one of the most impaired individuals in this study; he is able to go to work, refill and pick up his prescriptions, and perform other basic life functions.

The sixth family was the Archer family. The mother was Beverly Archer, a university student. Her son, Jake Archer (13), is higher-functioning with a diagnosis of “Communicative Autism.” Despite naming several interests (including cats,



wolves/werewolves, video games, and LEGO toys), neither individual was able to stipulate an overarching interest. Jake was also not entirely happy about participating, but his parents encouraged him to participate for a time. Jake complained a few times about the interview but was willing to share information when he found it humorous or satisfying to speak. He also joked around with the author, using childish repetitions.

The seventh family was the O'Neill family. The mother, Rachelle, and her son, Leonard (30) participated together. Leonard has Asperger's syndrome and had intense fascinations with Teenage Mutant Ninja Turtles, the Yu-Gi-Oh! Trading Card Game, professional wrestling, and Star Trek (particularly Star Trek: The Next Generation), as well as lesser interests in acting and reading.

The eighth family was the Sweeney family. The mother, Laurie, is a divorced working mother of two. Her eldest child and son, Walter, has a diagnosis of Asperger's syndrome with fascinations for dinosaurs, dragons, and the Nintendo Wii in particular, although he was also strongly attached to SpongeBob SquarePants. Walter was unaware of his own diagnosis and felt ostracized slightly at school for disliking the popular Star Wars: The Clone Wars because of its violence.

The ninth family was the Testarossa family. Melinda Testarossa is the mother of two daughters who both have a diagnosis of PDD. Her daughters are Kyla (16) and Tammy (14). Neither girl had any identifiably strong interests, at least enough to be deemed CIs. The mother said that their interests included reading, cooking, gardening, and shopping. One of the girls, Kyla, also had a coping strategy of leaving situations in which she felt uncomfortable; when irritated, she would leave the setting and perform tasks that she wished to do.

The tenth family were the Helsings. Victoria, the mother, participated with her

partner, Richard. They identified that their son, Billy, has Asperger's, as well as a love of science and engineering; when he was younger, he also had interests such as the Titanic. While Billy (around eight years old) participated, he was uninterested. He did not wish to think deeply about why he liked the things he liked or why other children did not like the same things he did.

The final family were the Lewis family. The mother, Leah, and her husband, Hans, participated at the same time, as did Leah's father, William Rogen. Leah and Hans' middle child, Jason (6), was the only individual in their family with an ASD. Jason participated afterwards, but tried to return to his computer games several times. While he did offer information, he showed a deep love of animals, especially dinosaurs – showing a knowledge unusual for his age. Because of his age and his diagnosis of mild to moderate autism, he was more interested in going back to his computer games than contributing to this study.

### *Ethical Considerations*

Ethics approval was obtained relatively quickly for this study. Laurentian University's Research and Ethics Board (REB) only stipulated one correction and gave approval during the Thanksgiving weekend of the second year of this study. A copy of the ethics approval is included in the appendix (Appendix D).

All participants signed consent forms indicating their voluntary agreement to the interview process (please refer to Appendices E and F). No instances of refusal occurred, though one participant, as previously mentioned, chose to use her right to withdraw from the interview process toward the end of her session. Given that most of the individuals with ASDs were legal minors, it was necessary to have their parents nearby at all times. All but one of the interviews took place with their parents directly present during the interview,

and in the sole case where the mother was not present she was readily available upstairs. In order to maintain confidentiality upon publication of the study, pseudonyms were assigned to all participants and any other people whose names were mentioned in the interviews; all data was kept confidential prior to altering the names. In most of the instances, the author revealed his particular diagnosis of AS; all the families that were told welcomed this revelation. Debriefings about the study were short, usually a mere thanks for their participation, letting them know about follow-up, and stipulating if there were any questions or problems to feel free to ask. Regarding mentioning the author's condition, this was quite casual, and often brought up within the interview itself.

#### *Analysis of Transcripts – Interpretative Phenomenological Analysis*

Transcripts were analyzed to find common themes in the data via Interpretative Phenomenological Analysis (IPA). IPA is a vehicle of qualitative inquiry whereby a researcher elicits detailed accounts of a participant's individual personal experiences and the participant's perspective of how she/he makes sense of her/his personal experiences and social environment (Smith & Eatough, 2007). Smith and Eatough (2007) emphasize that the researcher is most interested in discerning the meaning that the participants have for the various events and experiences that they have in their lives and how they perceive those events and experiences. In IPA, after data collection comes analyzing this data, a process in which, after detailed readings of the transcripts, initial themes are generated from the data and then later those themes are refined.

In the present study, data consisted of interviews recorded by a digital audio recorder. Parents were gladly willing to participate, though in some instances their children were less enthused about being involved. Upon completion of the interviews, they were transcribed as accurately as possible into Word documents. Given the depth of immersion

into verifying the accuracy of the transcripts, the author felt that he had gained considerable memory of the events, solidifying his position as the primary research instrument, gaining the valuable insights not only from careful transcription, but also from being the conductor of the interviews themselves. Details into the specific findings of this study will be presented in the Results section.

### Chapter 3: Results

This chapter details the present study's results. It will outline the themes found in this study, include essential quotes from participants, and also use these quotes in an effort to support the themes. Quotations will be described in detail, with sufficient information so that the reader may get a glimpse of the perspectives of the participants.

This study found more evidence that CIs affect the daily lives of individuals with ASDs, both positively and negatively. As will be discussed in greater detail in their appropriate sections of this chapter, and later in chapter 4, substantial positive impacts of CIs on the socialization and motivation of individuals with ASDs were found during the course of this study. Negative effects were also found, also on socialization and motivation, but other minor problems were also described by the participants. This study also found more evidence that individuals with ASDs can, under certain circumstances, amass enough knowledge about their CIs that transcends the expectations – and sometimes knowledge – of their parents. Successful strategies for maintaining control of the individuals with ASDs were gleaned from the information provided by the parents who participated in this study, strategies that assisted in minimizing possible negative outcomes for their offspring from potential overindulgence in the CIs. Finally, the views of the individuals with ASDs on their interests were looked into, as their perspectives are the most important, since they are the people who have the particular “problems.”

Upon completion of transcription, the transcripts were read and re-read so that common themes could emerge. These themes were found via a process called Interpretative Phenomenological Analysis, as discussed in previous chapters, whereby similar data are matched together to create themes by reading and re-reading the transcripts of the data to find these similarities and writing down notes on the pages as to ideas and connections.

Several themes came to mind, but, as I will explain, several of them were either similar to others and thus had areas of overlap, or they provided too few examples to be substantial in a stand-alone theme. After reading one of the longer transcripts first to get an idea of what to look for, each transcript was then read while trying to look for similar themes. These themes were then matched with highlighters and other forms of underlining for other initial themes; several of these themes were combined as they were similar in concept (e.g. the interference of CIs on house work and school work). A master list of the themes was generated as a computer document, and a description of each theme was inserted before the quotes were placed into a table. Subsequent revisions of the themes – and re-arranging the quotes under the new themes – were saved as new separate documents in an audit trail.

In order to make the theme names more memorable and understandable for the readers, they were renamed with quotes from the participants. These quotes reflected the themes they represented. This study found five themes: “*He's Very Unique*,” which described the positive aspects of CIs, and also contained two sub-themes (“*They Do Every Single Thing Together*” and “*Have You Seen All the Star Trek: The Next Generation Episodes?*”); “*They Don't Realize that Not Everyone Lives and Thinks the Same Thing All the Time*,” which referred to the negative aspects of CIs and contained three sub-themes (“*He'll Stop People in the Street and Lift Up Their Pants to Look at Their Shoes*,” “*Could You Ask Calvin to Leave Mario and Dr. Octagonapus at Home? Cause It's Interfering with his Learning*,” and “*Look, Mom! It's Eating It!*”); “*We Couldn't even Pronounce the Names of These Dinosaurs, and Jason was Telling Us*” (parental impressions of CIs); “*You Can't Change Them, You Can Only Love Them*” (parenting strategies); and “*So I Can Do My Job at the Same Time and Observe the Weather at the Same Time*” (individuals with ASDs are

passionate about their CIs). To make it easier to recollect what the themes describe, please refer to Table 3 below.

*Table 3: Theme Names and Descriptions*

<b><u>Theme Name</u></b>	<b><u>Description of Theme</u></b>
He's Very Unique	Positive effects of CIs on individuals
<i>They Do Every Single Thing Together</i>	<i>Positive impacts on socialization</i>
<i>Have You Seen All the Star Trek: The Next Generation Episodes?</i>	<i>Positive impacts on motivation</i>
They Don't Realize that Not Everyone Lives and Thinks the Same Thing All the Time	Negative effects of CIs on individuals
<i>He'll Stop People in the Street and Lift Up Their Pants to Look at Their Shoes</i>	<i>Negative impacts on socialization</i>
<i>Could You Ask Calvin to Leave Mario and Dr. Octagonapus at Home? Cause It's Interfering with his Learning</i>	<i>Negative impacts on motivation</i>
<i>Look, Mom! It's Eating It!</i>	<i>More serious negative impacts</i>
We Couldn't even Pronounce the Names of These Dinosaurs, and Jason was Telling Us	Parental impressions of CIs
You Can't Change Them, You Can Only Love Them	Parenting strategies
So I Can Do My Job at the Same Time and Observe the Weather at the Same Time	Passions about CIs from individuals with ASDs

*“He's Very Unique” - Positive Aspects of CIs.*

The first major theme was “He's Very Unique.” This name refers to Victoria's description of her 8-year-old son with AS; she went on to elaborate that “Everyone knows that Billy's Billy” regarding how his interests, and the way he acts upon those interests, affect how others perceive their opinion of him. This theme refers to all the beneficial or positive sides to CIs. Specifically, it refers to any particular quality of the CIs that had some net benefit or positive effect for the individual with the ASD. It can be regarded as events,

situations, consequences, and other possible outcomes of the CIs of an individual with an ASD that are either beneficial, socially acceptable, confer no negative reaction, and/or have no net negative impact on any of that individual's activities, responsibilities, duties, or requirements from others.

All parents in this study identified positive aspects of their offspring's CIs, and most participants with ASDs spoke positively of their interests. In the younger participants, this lauding of their passions was primarily descriptions of them and why they liked them; for example, Liam McDiarmid would talk passionately and at great length about Sonic the Hedgehog – in his case, he also used body language to great extent, dashing and using hand motions to indicate running at cartoonish super-sonic speeds. Older individuals with ASDs were better capable of identifying how their interests related to social obligations and task management; for example, both Leonard O'Neill, who is in his early 30s, and Charles Bidan, who is in his early 20s, were both able to reflect on how their interests had an effect on their schoolwork when they were younger.

The particular instances demonstrated in this theme can range from major to minor in scale, from minute to grand. They can also be small in scale, for example, an interest that is not too distracting from the individual's work; a lesser interest, such as Travis Jackson's interest in video games, did not have any effect (positive or negative) on his class work. By contrast, interests can also motivate an individual, such as Charles Bidan using the topic of the weather to improve his public speaking. “They Do Every Single Thing Together” and “Have You Seen All the Star Trek: The Next Generation Episodes?” are sub-themes of this major theme.

*“They do every single thing together” - Using CIs to promote social interactions.*

This sub-theme is defined as positive consequences of the CIs of individuals with



ASDs in regard to interacting with other people, especially encouraging communicating and interacting with others. The concept of this sub-theme, social interaction, was an important concept from the beginning of this study, as social interactions are already impaired in individuals with ASDs (APA, 2000). It stood to reason that an interest that would further allow an individual to retreat from social interactions would be viewed quite negatively with the parents of these individuals. In this respect, it is possible for social interactions to be encouraged by using CIs, and this was seen as a positive aspect of the interests not only by the author of this study, but in the work of Boyd et al. (2007). In that study, the authors found that CIs could be used as motivators, as the children with ASDs in their study spent more time with peers if the peer had the object that the individual liked the most.

Often interests can be mundane or even generic; sometimes they can be quite odd, perhaps even bordering on socially unacceptable. In the case of the Aker family, the eldest son had an interest that evoked no concern, whereas the youngest's interest was particularly controversial. Their mother, Kathy, confided that:

With Graham, [his interests' impact on his social relationships] it is always on the positive side. Because his interests are very... generic. Like the frogs... it's not... like Lyle (*her youngest son*), it's not... a girly thing. So... it doesn't get viewed differently, because you like frogs, big deal... it's an open... general topic that ... could interest the majority of people.

While most of the participating adults were the mothers of their children, a few families had both parents share openly at the same time. One of these families was the Jackson family; in this case, the father, Denis, was more well-versed in autism and provided some interesting examples. He described how his son's CIs were surprisingly not

as much of a problem for their son's social life at school as they had thought. “But apparently that EVERY SINGLE KID said 'Yeah, sure, I'd be happy to go over to his house.' So... if [his interest in plane crashes] does interfere.... either it doesn't bother them... or it doesn't interfere.” Denis also reinforced this idea when describing how Travis would interact with other children in public. Using an example from a local museum, he described how Travis was able to interact with unfamiliar children in a positive way:

Yeah, I think people see [airplanes] as an IN rather than an OUT – not exclusionary. ... at the [air plane museum], for example... he'll be sitting in one of the airplanes and another kid will come in with him and then he'll start talking to him like the kid's the co-pilot.

Not all interests should evoke an automatic negative response. In fact, they can be used to help motivate social interactions. Betty McDiarmid, a mother of two young boys with autism, elaborated:

If I let them [play games regarding] Sonic [the Hedgehog], for example, the interest went from playing a game, to playing it life-like like, with friends. To now making their own videos that they want to put on YouTube. For me, it - it shows, it shows that there's a GROWTH happening, number one. And that they're not limited to – yes, it's Sonic – but they're not limited to just playing the video game. In – in a little bubble – by themselves. And... THAT, at least, allows me to spend time with them, like with the videos they – they'll SHARE their story with me. They'll show me how they're building it. By taking it beyond and trying to get them to... um... INTERACT in a different way as a learning outcome instead of... instead of their own little thing with Sonic.

As Betty demonstrates with the example of her children, CIs should not be seen as the isolators that they are perceived as in the lay culture. On the contrary, they can even help motivate children with ASDs to find a way to express themselves and become sociable with other people. In this instance, it allowed the brothers to find a way to share their interests with their mother, and to even find a way to express themselves to the online community. At the very least, encouraging individuals with ASDs to use their constitutionally guaranteed freedom of expression is an admirable goal.

*“Have you seen all the Star Trek: The Next Generation episodes?” - CIs as motivators.*

This sub-theme describes the effects that CIs can have on individuals with ASDs that may encourage them to perform a certain task. These tasks may be schoolwork, jobs, homework, chores, and other activities that are not necessarily enjoyed, but important, to the individual. The level of encouragement may have an impact, as a person with a primary interest related to the task may be more spurred to perform that task and to perform it well, as compared to a task associated with a secondary interest, or no interest at all.

Some families have expressed concerns about getting their children to do things such as homework or household chores. Kathy, by contrast, was quite exuberant in saying that her eldest son, Graham, could be so easily motivated by his CI of frogs: “You can make him do anything...it’s a huge motivator. It’s, it’s one of those things where it does not get tired of. Where some things you know after a while...there is no limit to this...” Her son's love of frogs, which she also described as involving sleeping with a massive amount of plush frog toys and becoming heart-broken if a frog were to be killed in a documentary, could be utilized by Kathy to get her son to do his chores and schoolwork. Her description of “there is no limit to this” implies that it is successful under the circumstances she has

used it in, which implies that virtually any situation could be made easier with promises of amphibians of the biological order *Anura*.

The positive side of motivating children with CIs is not just limited to the home. The stepmother of a young man fixated on the weather, Emma Bidan shared how her stepson Charles was motivated to share his interest in a positive way when he was an elementary student, and how that branched out into other areas:

Yeah, and they played on his special interest, to get him interested, and... you know, talking to the kindergarten kids, giving them the weather forecast, and that branched off into public speaking... you know? So, he got awards for public speaking. And they went way above to – well, he always had an EA – but they went way above to help him memorize his presentation, and helped him write it, and everything. So, he was able to be really successful in school. He got awards for being a good citizen.

There are legitimate concerns involved in this concept of motivating people with ASDs to do their specific tasks. Sometimes they can possess certain traits that are not condoned by society, for example taking pride in doing work and not giving full credit for where the ideas originated – such as copying someone's work. Additionally of concern in this plight are the difficulties in rearing children with ASDs; in the context of this study, Maria Britannia, whose eldest child used to have a tendency to claim ownership of drawings that she copied from her friends, was able to remove her daughter's tendency to infringe on the intellectual property of her friends. To correct this, Maria described a process of positive reinforcement:

So what I'll do to fix [Euphie's copying of friends' picture], is I take the friend aside quietly, and I say “Euphie really likes sharks. Go to a website

and ask her if she thinks she can draw it – that shark. But pick out a JPEG that’s... a photograph, not already hand-drawn.” So change her interest to what you’re drawing into something she can call her own, like a fish, instead of drawing a character that the friend was drawing. And give her a lot of positive reinforcement and tell her she’s really good at it, as she’s drawing it so that... she – she finds something – she takes ownership of something of her own state “Hey, that’s really cool, you try to draw that.” ... Fixed the problem.

According to this study's participants, CIs are not the problematic obsessions that they were once viewed. The ability that CIs have to motivate people who have these interests should not be rebuffed as hindrances to proper societal interactions/obligations. Rather, they should be seen as sources of pleasure for individuals with ASDs and should be utilized as reinforcers of desirable outcomes. While this notion is true, it is not universal: much like in parenting in those children who do not have developmental disabilities, if they are left to their own devices, their interests can devolve into more problematic issues and fail to motivate people with ASDs.

*“They Don’t Realize that Not Everyone Lives and Thinks the Same Thing All the Time” - Negative Aspects of CIs.*

This is the second major theme of this study. The name comes from a statement given by Betty McDiarmid describing her children, and how they have not yet developed an ability to see that what others want is different from their own, before elaborating that her children will revolve their lives around Sonic the Hedgehog.

This theme refers to any particular quality of the CIs that was a detraction for the individual. It is defined as events, situations, consequences, and other possible outcomes of

the CIs of an individual with an ASD that confer no benefit, are not socially acceptable, result in undesired reactions, and/or are a detriment to any activity, responsibility, duty or requirement. All parents identified aspects of their children's CIs that were negative. The parents also tended to focus more on the problems and issues than the successful qualities, often detailing extensively specific issues around social detriments and deficits in task performance. Of the individuals with ASDs, most did not offer any information that demonstrated negative aspects of their interests.

One possible explanation for their responses may be age: while most of the younger participants did talk about their problems with peers, they did not seem to be able to make the connection that their interests might be a factor. Of the younger individuals who participated in this study, Travis did not talk about any problematic issues; Liam and Patrick both stated that they were bullied at school, though Liam did state that his differences, however minor, with other kids were due to how his peers “they know Mario, but they don't know Sonic. They just don't know;” Jake did talk about having some difficulty with other kids his age but this was also not as significant; Walter noted that the other kids his age would prefer their playing with Star Wars to his dinosaurs and dragons; both Kyla and Teresa offered very little, though it appeared that any problems were not due to their interests; Billy did not acknowledge any issues at all; and Jason was too young to comment. The two older individuals, Charles and Leonard, were able to offer insight into their youth that may have come with maturity. They tended to add details of negative perceptions by others and areas where they tend to waver in getting tasks done. By contrast, the younger participants did not appear to fully recognize that their interests were not shared by others and could not comment on such issues. When the younger individuals did note areas of discrepancy with their peers in terms of what they liked, they did not appear

to understand why other children did not like the same things they did.

As with the first theme, participants identified aspects of CIs that range from major to minor. The negative aspect sub-themes include “He'll Stop People in the Street and Lift Up Their Pants to Look at Their Shoes,” “Could You Ask Calvin to Leave Mario and Dr. Octagonapus at Home? Cause It's Interfering with His Learning” and “Look, Mom! It's Eating It!”

*“He'll stop people in the street and lift up their pants to look at their shoes” -  
Socially inappropriate actions and CIs.*

The name of this theme comes from Kathy Aker's description of her youngest son, Lyle. In the context of the quote this title was based on, Lyle had a fascination with shoes, particularly the shoes of women. In some cases, he would go up to strangers and inspect their shoes out of curiosity and fascination. A young male looking at shoes would be slightly worrisome for some parents as a strange enough feat, but to go so far as to lift up their pant legs or even dresses just to do so is not an appropriate action, especially in public. It was felt that this innocent, yet unintended invasion of a person's personal space would be a very appropriate name for a sub-theme about actions that are not socially appropriate.

As mentioned above, this sub-theme refers to events and tasks performed by an individual with strong CIs that are not acceptable in the broader social context. The interest's power over the individual may prevent that individual from forming close relationships with others, may prevent interactions with others, and may lead to being socially ostracized by others. These activities can include very personal questions without regard for potential embarrassment on behalf of the respondent, or performing actions that are not publicly acceptable, for example.

The activities expressed in this category do not necessarily need to be extremely

inappropriate but include activities that are more benign, though still generally undesirable. For example, when Charles was younger he had an interest in medicine, and would ask people rather invasive questions about their medical histories. His step-mother, Emma, in describing his childhood medical problems, having to spend a lot of time at the Toronto Sick Kids Hospital and developing a fascination with “all things medical. Tubes, and needles, and.... Oh my god! It was AWFUL. He was SO interested in all things medical. This was an ALL overcoming special interest for years. Then finally... and I think a lot of it has to do with his uh... WISH to be socially accepted ... Because all this medical talk was NOT socially ... cool. It's not cool to ask people if they've ever had a catheter. Sorry!” Here is but one example of a participant going too far with their interest and asking embarrassing and personal questions to other people.

For humans there is a necessity for social bonding: while, as a social species, we should be encouraged to meet with others, especially friends and family members, the extent one should be forced to do this is more debatable. It is necessary sometimes for a person to meet new people whether they would prefer to do so or not, but for people with ASDs, forcing them to be as gregarious as a “social butterfly” is impractical and would only create more stress and discomfort. With this concept in mind, it is easy to see how this could be a problem for Maria, who described how her oldest son was uninterested in family gatherings. As hard as this probably was for Maria, she was cognisant enough to realize her son's limits and try to adapt to the situation, showing a heartening adaptation for parents. Specifically, young Calvin would shy away from extended-family bonfires in favour of his own preferences: “That idea of... being a family at family gatherings is not... I've let it go. ... They're always saying, “Where's Calvin? Where's Calvin? And where's Calvin?” Well, he's drawing in our camp ... drawing and playing plasticine. I WISH he could be



with us, but I can't change that. ... “Well, no, he'd prefer to be alone and play” So I bring a respite worker so he's safe.” Most children with ASDs will never be able to adapt in the way that their parents want them to, so sometimes it is prudent and wise for the parents to do some adapting. Maria demonstrates how much she wants the family to bond but must suppress her own desires for the sake of her son's well-being and happiness.

CIs can have effects on peers and parents. However, siblings are another group of people who may be marginalized by the demands of their siblings with ASDs. Laurie Sweeney, mother of an elder son with Asperger's and a younger daughter with no ASDs, described how her daughter will often have to submit to the desires of her older brother in regard to the television. The boy, Walter, displays trouble sleeping when he has not been able to watch a favourite movie or TV show prior to sleep; that situation causes controversy with his younger sister who sometimes wishes to see what she likes: “[She] ends up having to do – watch whatever he's watching. ... It's kind of a little bit unfair in that way. He gets to pick the movie. I try to... get – give her a chance every now and then. I try to explain to him that she's gotta have a turn.” Children with ASDs are still human beings: they should not be denied their own desires out of hand, but at the same time their will is not autocratic. Laurie has a conundrum whereby she must balance the desires of her children. While Walter has some issues with sleep, Laurie should not have to choose between her daughter's happiness and having a son with insomnia.

Kathy's youngest son, Lyle, had described earlier that she has some concerns with his particular CI, as it is unusual and socially awkward for a boy to be interested in shoes, much less the shoes of females. She expressed some concern, especially because her husband was more traditional and less tolerant of views that violate accepted gender norms; however, despite being aware of the nature of this interest, she was also accepting of it.

“It’s uh, it’s uh one of those things where as he gets older, it’s not really something you can really carry through. Cause then you end up bringing more, you know, stigma to that ... Well, you dress up like a girl, Lyle. And... I don’t want to make things more difficult than it needs to be for him.” Kathy's dilemma is not always an easy one to make, but even if she does choose to make her son's life happier, they both have to deal with societal norms and expectations. Lyle's preferences, if they continue with age, may bring unwanted problems for Lyle and his mother.

*“Could you ask Calvin to leave Mario and Dr. Octagonapus at home? Cause it's interfering with his learning” - The interference of CIs on tasks and duties.*

This sub-theme's name originates from a quote from Maria. One of the teachers for her son, Calvin, asked her to assist in having him stop engaging in his interests for Super Mario Bros video games and the internet meme, Dr. Octagonapus (a parody of the Spider-Man nemesis, Dr. Octopus) during classtime. This sub-theme refers to activities, actions, and/or events that may prevent, delay, or prolong an individual's performance with a particular task. The author defines a duty as any task that is mandated to be done by others in a position of authority over the individual. These duties or tasks may be from, but not limited to, society (such as civil responsibilities, like reporting crimes), from parents (such as household chores), from teachers (doing one's homework), or from an employer (tasks related to that individual's profession, career, or job).

Much like the sub-theme *“Have You Seen All the Star Trek: The Next Generation Episodes?”* that addressed the issue of potential motivation resulting from CI engagement, this sub-theme involves the issues of people with ASDs and their relationship with performing chores, studies, and jobs. As such, this sub-theme refers to the negative aspects of CIs in regard to duty/task performance. One of the best ways to illustrate this idea is

with children and their schooling. Victoria Helsing, mother of a young boy with Asperger's, described her son's behaviour at school. Specifically, his teachers have been able to see his potential and good scholastic ability, but have some problems with maximizing it. As Victoria explains,

Yeah, [the teachers] wanna kind of... you know, help him, like, express himself, I guess you could say. But at the same time, you know... They kind of 'Billy, you're here to go to school, you know, you – you need to do your work, you need to stop talking' you know, they kind of keep him on... the academic side of things, because he IS academically very bright. Even though he has all [these] disorders. Like, he is working AT grade level, if not above...

Other families have expressed similar concerns in regard to school. Betty opined that the interests of her sons do have an effect on their duties at school, specifically that they would ignore doing work during work-periods and focus on drawing. “Uh, it does have an impact, for example at school we’ll get reports that my youngest um... instead of doing their homework or whatnot, he’ll just sit there and draw the characters. Over and... and talk about that. And he’ll – he’ll veer off subject. So it gets difficult at school, too, in that sense...”

Not all of these duties are school-related, or even related to the individuals themselves. Sometimes the effect of CIs can hinder the parents' abilities to get work done, since they are distracted from household chores like cleaning to care for their children. Melinda Testarossa describes an activity one of her daughters had in her childhood. The following is a dialogue with her daughter expressing her opinions on the matter as well:

Melinda Testarossa: And she had a repetitive thing that she did. And... and

she would... take... toys and whenever, and it would always be putting it in to another container. Or... Like, just from one container to the other container, not really PLAYING... with toys...And... and she'd take paper, and she'd cut paper in to squares.... Remember that? Cutting/

Kyla Testarossa: I don't even remember anything! Like, like, I just remember what happened... like, today.

Melinda Testarossa: Oh. When you cut paper into squares.

Kyla Testarossa: I remember making snowflakes... I remember shoving/

Melinda Testarossa: If – if you made something, it was always that same thing, you made.... over and over for a while. And then... maybe you'd change. And then you'd make something else over and over and over and do something – something repetitive.

While this example does not specify a particular outcome, other studies have reported that individuals with this have some form of RRB, especially when repeated numerous, have the effect of delaying the ability to get things done (i.e. Mercier et al., 2000). This particular instance still illustrates how even the most rudimentary form of CIs can still disrupt the activities of others.

*“Look, Mom! It's eating it!” - Problematic outcomes of greater concern.*

This name comes from Leah, who quoted her son, Jason, when he showed her a video of a python eating a bovine. Her simultaneous shock from the event combined with her humorous recollection of that event was whimsical as well as cogent, and seemed suitable for describing a sub-theme about inappropriate pursuits of CIs that have results distinct from interference with socializing or duty completion. This sub-theme refers to any action or behaviour that is employed by a person with an ASD in regard to their interests

that does involve interfering with one's ability to socialize or to perform duties.

Problematic behaviours are generally more of a concern than interfering with duties or inappropriate social activities.

This sub-theme is exclusively negative in origin. It was created to encompass undesirable consequences of CIs that did not have a relation to social or task-related aspects, but were still quite problematic. The target of the problem can be either the individual or others, including the parents, peers, teachers, or strangers in the public: in the case of the quote to illustrate this theme, it is more problematic for Leah and Hans, who, like most individuals in the typical-developed population, might be more prone to disgust at seeing one animal eat another; in other cases, it could be more problematic for the individual as well. Using the same example, Jason, if left to his own devices, might become more desensitized to such acts, or similar acts of violence. Often the problems described in this sub-theme are ones that are more publicly unacceptable or even suspicious in the eyes of other people without being linked to socialization.

One particular aspect of the problems can be the actual interests themselves. As opposed to hindering social interactions or hindering getting chores done, the very nature of some CIs can be troubling. One example was expressed by Travis, Denis' son. His strongest CI at the time of the interview was plane crashes, with explicit detail of some of the most well-known incidents in airplane history. While he has shifted his primary CI to cars, he still has an interest in airplane crashes. Said Denis, "He watches um YouTube videos of of plane crashes, it's actually kind of disturbing." Similar to Leah's reaction to Jason's viewing of feral carnivorism, parents might be more concerned if their children are more disengaged from the reality of death. Denis, like the average individual in the population, would likely be shocked by others finding humour in mass destruction, a

possible sign of significant psychological problems. Given the kind of damage to property and the death toll that can come from such events, Denis' concerns are well-placed. Denis also recollected how, at the airplane museum, Travis was yelling inappropriate things. “I think it would be kind of funny, to be honest with you. I just hope he doesn't do like he did at the [museum] once: in – in – you could hear all [through] the museum, him yelling, you know “I'm a terrorist! I'm hijacking the airplane!” and he YELLS it and the place is cavernous” This would most likely cause shock to others, especially in a place filled with planes. Denis' ability to take a joke and be more relaxed regarding the situation appears to be a sign of reasoned parenting, a strong connection between father and son, and an ability to empathize with his son's interests. Denis also mentioned that he hoped he could take his son on an airplane trip one day, but felt somewhat discouraged by his son's age and immaturity, feeling that repeated behaviour at an airport or on a plane could lead to serious ramifications.

Some interests can be benign, sometimes it is the extent that they are adhered to that can be the problem. Even without interfering with duties or social interactions directly, the extent to which people will pursue their CIs can sometimes have negative consequences. This drive and intensity has been looked at by others, including the aforementioned Woodbury-Smith et al. (2010), who looked at the relationship between the CIs of individuals with ASDs who had been convicted of criminal offences and the CIs of those individuals who had never committed a crime. It is possible that the intensity might even be the main factor in these problematic behaviours, as the individuals' passion and devotion to their interests can sometimes conflict with things that are more important, including duties, social responsibilities, and even necessities such as sleep. Beverly Archer described her son's fascination with LEGOs and the extents he went on to complete the kits:

He used to [have problems with focusing on interests]... if he was focused on it, that was it, you can't get him out of it, yeah. But – as soon as he starts anything, he has to complete it. ... [So], with the LEGO kits, as soon as he started a LEGO kit, he had to finish it. And he would stay up ALL night if he had to, to complete a LEGO kit. Of, like... 20,000 pieces. So, it's one of those... where he starts something, he has to finish it. And he has to finish it, cause if he doesn't, then... it just works him out.

It is good fortune for people to have interests that they are passionate about, but when it becomes apparent that pursuit of the interest begins to interfere with one's own health and well-being, intervention may be advisable. This kind of passion for getting tasks completed may be useful in the workplace, but the extent to which it is carried out is startling.

Beverly's desire to rein her son in from doing so is understandable, but enforcing it could be more problematic. While she did not seem too concerned, implying she had her son's health in good control and that this occurrence was not a nightly activity, failure to keep this obsession controlled could result in disrupted sleep periods for Jake; success might mean disrupting her own sleep to monitor her son.

While most of the interviews were conducted with the children giving their side apart from their parents', one family, the O'Neills, opted to have both mother and son present at the same time. This format provided a unique insight, as well as the opportunity for both groups to counter statements made. The young man, Leonard, described his fascination with the trading card game franchise Yu-Gi-Oh!, and how his interest would provide a source of concern to other people. While this specific interest does not interfere with his abilities to socialize or do work, it was more of a strain on the family, as they often had to put up with his interests, including his insistence on going to card game shops while

on vacation, or to tournaments locally or even out of town; it even proved a problem with him, as taking his collection around can be quite cumbersome. “Well, when I was younger, with the Yu-Gi-Oh! And that...I'd carry a backpack of the cards. If I was going on a trip, I'd have them with me. In case there was a chance to play someone.” To go to the extent of bringing such possessions, especially considering the ramifications including risks such as loss or theft, or the effects of physically bringing such things along such as weight, may be an issue of concern. Leonard sees no problem with it, but his mother does. She has stated that while she has no inherent problem with him playing a children's card game, she is concerned by what he will do to engage in it. She made clear in the interview that Leonard would not likely be able to go to Ottawa later that year for his tournament because of fiscal restraints; this led to a curious and interesting debate between the two about Leonard's insistence on going and Rachelle's rebuttals with reality.

While it may be that the intensity may be the issue to these problematic behaviours, as demonstrated in the above quote selections, one should not lose sight of the overall issue of problems regarding CIs. Yet one should not forget the larger issue either: that these CIs are inherently important, to the individual, and the ramifications are important to others around the individual. But the intensity is not a bad thing, either: as the next major theme follows the abilities an individual with a CI has that are most impressive.

*"We Couldn't Even Pronounce the Names of These Dinosaurs, and Jason was Telling Us" - How Parents are Impressed by the Abilities of their Children.*

In the present study, one particular pattern that was noticed was that every single parent had something positive to say about the interests (this was particularly true when the interests were strong enough to be described as circumscribed interests). Curiously enough, parents would even volunteer their support of these interests in some form, or acknowledge



this information without delay when pressed. This theme name comes from the Olou family, who recounted how their son Jason received for Christmas one year a video about dinosaurs. As he was dancing along to the songs, his parents noticed that the names of some of the creatures were difficult to say, whereas Jason had little to no difficulty.

Certain patterns emerged from the data that coalesced around this idea that parents were astonished or proud of their children because of their abilities. All of the parents voiced recognition of benefits that these interests took in relation to either social interaction (see *They Do Every Single Thing Together*) or task completion (see *Have You Seen All the Star Trek: The Next Generation Episodes?*) The way parents voiced their approval, or the follow-up/explanations of these are what formed this theme.

One way parents voiced approval of the interests was in the form of amazement at the abilities their children have despite their chronological and/or developmental limitations; as demonstrated with the name of this theme, despite Jason's young age and moderate diagnosis of autism, he was still adept enough with all things dinosaur that he could best his parents in the pronunciation of some of their names. Another pattern was when parents described phenomena that they had become so familiar with, the initial amazement had vanished; this amazement had been replaced by a more familiar feeling of pride in their offsprings' abilities. For example, Betty talked with much pride in her voice about her children using their interests to play together and expand as people. Another pattern was that parents would even describe ways in which they agreed with the interests, or perhaps even possibly shared them. Laurie commented that she had seen so many episodes of *SpongeBob SquarePants* at Walter's behest that she had started to like the series herself. Emma confided that, like Charles, she loved to be around certain storms, though the way she expressed this could sometimes come into conflict with Charles' preferred

methods. Namely she did not mind swimming when a storm was brewing, but Charles would become erratic and fearful, insisting against swimming with the possibility of lightning.

Some parents were particularly impressed with the memory abilities of their children. One aspect of autism that impressed even some of the earliest researchers was the memory that their patients had for certain things, such as Dr. Asperger's "Little Professors". In the case of the Jackson family, young Travis displayed prodigious information about plane crashes, to the point where his parents identified that his knowledge may stretch to every civilian, commercial plane crash dating back to the 1930s or 1940s. Travis' mother, Taylor, went on to say that Travis "seems to... have uh... a visual memory where he can remember every detail he will have heard, or read, about this one... plane crash" while his father, Denis, elaborated with "Yeah, so I think it varies from plane crash to plane crash." The details Travis has for planes are not just limited to civilian planes. His parents also spoke of a strong fascination he had with warplanes and helicopters as well, particularly from the time period of World War II. Taylor briefly described his abilities: "He can name planes, too. Like, he can name bombers, and... and... Second World War bombers, he can name them. And helicopters, he can name helicopters." Travis' father, Denis, followed up by saying that "he knows the make and model of a lot of planes." During the interviews, it was easy to tell that Taylor and Denis were impressed with Travis' abilities despite his limitations. His prodigious knowledge was tested when the author interviewed Travis, though he had to be encouraged by his parents to give the answers necessary. Denis would coax Travis into giving the answers as he was too shy to do it himself, and when Travis did respond correctly, Denis would congratulate him and reinforce him with such phrases as "I knew you could do it."

One may be tempted to think that all CIs are on specific topics that few among those whose development was average would enjoy. This is not the case at all. In some cases, the passion that the individual with ASD has can also be enjoyed by the whole family, possibly even inspired by other family members. In the case of the O'Neills, such a situation applies to the Star Trek franchise. Not only did Leonard, the eldest participant in this study with an ASD, show a strong interest in Star Trek, confiding after the interview to having the autographs of several infamous Star Trek: The Next Generation actors such as Jonathan Frakes and having read many of the Star Trek novels, but his family also enjoys Star Trek.

Interviewer: ... aside from, uh... what you mentioned with my first question, uh, what are some of your interests?

Leonard: ... Ninja Turtles... comic books... wrestling... chess... improv... reading...

Rachelle: Star Trek.

Leonard: Mostly St – Star – I like, I like Star Trek.

Rachelle: The whole series, all the way to like, Voyager, down. What's the other one? The Enterprise?

Leonard: Eh, Star Trek, Star Trek: The Next Generation, Deep Space 9, Voyager, and Enterprise... I read mostly Next Generation, Titan, and... Voyager novels, now. ...

Rachelle: Star Trek is something we've all -

Leonard: Yeah. Star Trek. Grew up on Next Generation. ...

While this particular quote could do more to show in more depth how the O'Neill family likes Star Trek, comments made by Leonard and Rachelle afterword demonstrated that it

was a shared interest. While this topic would have provided more data if it had been followed-up with more questions, the fact that Rachelle was willing to volunteer this information, and that Leonard indicated having been exposed to and growing up with TNG as a child indicates that the family enjoyed the show greatly. Later in the interview, Leonard discussed a situation where he and his father had recently started a tradition of going to Toronto for a particular convention. This topic was not followed up with, but while the audio did not properly describe the event's name, it was likely a science fiction convention. If the author's assumption was correct, then this event would tie into the idea that family members other than Leonard are engaging in one of Leonard's CIs, further reinforcing that they are willing to do something with Leonard and not just for him.

It should be noted that in the case of the parents, two of the fathers had been thought to have autistic-like symptoms (as described by self or spouse), though no formal diagnosis had ever been applied. The degree to which the majority of the parents would be interested in what their children liked would be limited to how parents without developmental disabilities perceive interests. In the case of these two fathers with autistic-like traits, Kathy's husband did not share any interests with his sons, while Denis shared several of Travis' lesser interests, predominantly video games such as Halo and Call of Duty, but also topics regarding war.

*"You Can't Change Them, You Can Only Love Them" – Parenting Strategies.*

In examining the data, a pattern emerged that was distinct yet related to the topics of socialization and motivation. While it was important to inquire with the participating parents about the interests of their children, and vicariously how they responded to both positive and negative outcomes of their children's indulgence in their interests, specific styles of parenting were never investigated. Despite the lack of enquiry on the topic, it was

apparent that in some of the families there were different philosophies on child-rearing and how such styles were employed. The approach a parent takes to raising their child and helping him/her overcome certain syndrome-related limitations makes a difference: the majority of the parents in this study demonstrated ways in which they helped their children in respect to their interests. It seemed apt to not just highlight specific instances of the different styles of parenting, but also to reference the work of Diana Baumrind, whose research has provided much insight into these different parenting styles.

Baumrind (1966) postulated three parenting styles: authoritarian, permissive, and authoritative parenting. Authoritarian parents attempt to control the behaviour and attitudes of their child according to set standards from on-high, and value obedience, punishment as a response to deviations, and restriction of autonomy. Permissive parents, by contrast, are more accepting of their children, and favour consultation and explanation, make less demands, allow for self-regulation, reject punitive actions, and establish control diplomatically. Authoritative parents hybridize the best of these two styles: they explain and encourage negotiation of rules and listen to objections, but also exert control (via redirection and explanation, as opposed to totalitarian means) and enforce their position as the parent.

The theme represents how parents address the ways in which their children engage in their interests. Their response to less desirable outcomes is somewhat indicative of their preferred parenting style. Whereas some parents might prefer to extinguish an idiosyncrasy by disciplinary measures, some parents might prefer explanation and negotiation. Regardless of the specific method employed, it was apparent that the parents in this study were effective in maintaining control of their children and cared for them deeply.

A sentiment expressed by Maria Britannia seemed appropriate to describe not just a

necessary realization for any parent of a child with a disability, but the proper motivation behind any style of child-rearing: love for their child/children. Maria's statement indicates not just a healthy acceptance of reality, it highlights the level of maternal care she has for her children. It was taken from a portion of her interview where after explaining to relatives what to buy as a present for her son – and how her son would be more interested in getting paper, markers, and staplers than the type of present for any other boy of his age – she briefly touched on how she's had to explain to other people, including family members, as to how her children are distinct from other children. She admitted to being exasperated from having to repeatedly explain such distinctions but was nonetheless glad that her parents had finally begun to embrace the fact that their grandchildren were different. Her statement also indicated that there would be only futility in attempts to alter her children in a profound enough way that they would either no longer be autistic or where mitigation would compromise their well-being; the best course of action to her would be to just accept the children for who they are and love them for who they are.

Maria Britannia had one of the most serious of circumstances regarding child-rearing in this study, as all three of her children have ASDs, the youngest having the most severe impairment. Despite the circumstances, her viewpoint of positively reinforcing her children's interests demonstrated her abilities as a parent to help her children be happy and express themselves. Reminiscing on previous situations around Christmas time where other family members would ask her what they could get her middle child, Larry, as a Christmas present.

We've taken those interests... and built upon them. So, for example...

someone will say, 'What do I get Larry for Christmas? You know, he's 10.' I said, 'Well, don't go buy the age 10, he would be... more than tickled if you

got him 3 reams of white 8.5 x 11 paper with two 6-packs of magic markers... and a stapler.' So take the interests and build on them. It might be odd sometimes... you can't change them, you can only love them, right?

Maria, an advocate of helping families who have children with ASDs, prefers positive reinforcement for raising her offspring. She indicated later in that interview that her viewpoint on her youngest's repetitive behaviour of head-banging was that so long as he was not harming himself or others, he was expressing his happiness at a certain phenomenon and that interfering would not be appropriate.

Another strategy was to apply more discipline to remove the problems of overindulgence in the interest(s), and prevent the interest(s) from becoming “crutches” or excuses. Emma Bidan at one point in the interview expressed her frustration with many youths, insinuating that they are spoiled. Showing her contrast to this form of child-rearing, Emma described how she eliminated some of Charles' bad habits as a child. While this particular incident did not refer to CIs specifically, this demonstrates the style in which she was able to influence Charles to abandon certain more detrimental elements of his interests when he was younger, such as enquiring about other people's medical histories.

Then he would ask the question again, and then he would get told, 'I'm not prepared to discuss this subject again until... AFTER supper.' ... And, and that worked. As long as you're consistent, it's like training a dog. It worked. If a dog is being annoying, in any way, shape or form, tell them to lay down. They're all jumping, licking, getting in the way – tell them to lay down. It's the solution for ALL bad behaviour – er, intrusive behaviour.

By contrast, Emma also demonstrated that she was equally committed to raising well-adjusted children who could explore their interests. Much like with Maria, Emma described

situations where she reinforced her child's interests by helping them gain certain experiences. When Charles was a child, she organized a tour of The Weather Network.

He wanted to tour the Weather Network. Well, I contacted the Weather Network and they made him his own special tour, just me and him. ... We went to the WN, and he got to sit in the Weather Girl's chair, and talked to the real Weather Girl, and he got to speak to the meteorologists... and, Oh! He was in his element. He was – he went on about that forever. He was so happy.

*“So I Can Do My Job at the Same Time and Observe the Weather at the Same Time” - Individuals with CIs are Passionate About Their Interests.*

The individuals in this study whose interests were strong enough to warrant a subjective diagnosis of having a CI really enjoyed their interests. Other themes in this study detail important benefits that these themes have, but one must not forget that first and foremost they actually enjoy these subjects. This theme refers to the passions, thoughts, and feelings that the individuals with ASDs described themselves.

Leonard O'Neill, for example, demonstrated quite easily how much he cares for his interests. One of them, the original Teenage Mutant Ninja Turtles franchise, was so strong that he still lamented deciding against purchasing a TMNT product when he and his mother were in Pittsburgh, Pennsylvania to participate in a study on autism several years prior. According to Leonard, “[I] still wish I had grabbed something I hadn't grabbed down there. A giant Ninja Turtles... It was STUPID of me not to grab them when I had the chance.” Leonard also showed videos to the author after the interview where he had, in recent years, participated in a TMNT costume-play contest at several conventions. His passion for the Turtles was certainly very strong, having maintained the interest into his 30s.



People with ASDs can even go so far as to express their interests even at the cost of social standing or some form of alienation. Liam McDiarmid, for instance, commented on this to an extent. In his case, his love of Sonic was not shared by many of his peers. Whether his assumptions are accurate or not, given his age, the fact that he has to point out to his peers that they should become familiar with Sonic the Hedgehog given the character's popularity compared to its former rival, Mario from Super Mario Bros. Liam's explanation for his peers' ignorance about Sonic was that, "They know only Mario... Only me - only me and Siddig knows Sonic. Cause Siddig has Sonic Unleashed for Wii. ... They know Mario, but they don't know Sonic. They just don't know. .... I tell them to go and sti – to look at the SEGA aisles, but they don't. They don't know what SEGA is." In the defense of his peers, it should be noted that Liam was about 11 at the time of the interview, and that SEGA had been bankrupt for several years prior to the interview, so there would no longer be any "aisles" for shop owners to display SEGA games (unless the games are in a pawn shop of some sort). For Liam to say that his peers do not know about Sonic, whether by circumstance or willful ignorance, is a statement that could bring him in conflict with his peers. It is hard to envision anyone doing this if they did not care about something this much.

In other cases, the desires may bring an individual into conflict with reality. For Walter, a young boy, the distinction between dinosaurs and dragons is as real as either type of creature. While dinosaurs were clearly among his most prevalent interests – an interest common in young males – Walter was also interested in dragons. Much like our ancestors in more intellectually devoid times, Walter believed that the two could be easily confused. As he explained his interest in dragons, he also showed this interesting bit of naïveté:

Oh, dragons? I like them because... hm... well, it's like... like... dragons...

what I like about them is that – you don't – you never know if they're really real or not. Maybe they were real and people were – there, but they just sink were there. And maybe they found a bone of a dragon but they thought it was a dinosaur, and... so they placed it in a museum, like that. ... Yeah, like a dinosaur bone, but they... it's a dinosaur bone, but it's a dragon. You never know.

Walter's fascination with dinosaurs and dragons is not uncommon in children his age, nor is his belief in the possible existence of dragons. His willingness to put preference of these at the cost of what his peers wish to do is an indication of his own passion and love for those interests. Like the other themes described above, one can see how these interests shape the lives of these individuals and the people who love and care for them. The final section of this chapter summarizes the findings presented above.

### *Conclusions*

Five themes were discovered in the course of this thesis. “He's Very Unique” was a description of positive benefits to the interests, and contained two sub-themes: “They Do Every Single Thing Together,” which describes how the interests can promote social interactions, and “Have You Seen All the Star Trek: The Next Generation Episodes?” describes how the interests can act as motivators. The second theme, “They Don't Realize that Not Everyone Lives and Thinks the Same Thing All the Time,” refers to the downsides of circumscribed interests and had three sub-themes: “He'll Stop People in the Street and Lift Up Their Pants to Look at their Shoes” was about the socially inappropriate actions that occur as a result of pursuing their interests; “Could You Ask Calvin to Leave Mario and Dr. Octagonapus at Home? Cause It's Interfering with His Learning” was about how CIs can interfere with the individual's ability to do what they are required to do, whether by

their parents or teachers; and “*Look, Mom! It's Eating It!*,” which described more troubling scenarios that result from engaging in interests. The other themes in this study did not have sub-themes: “We Couldn't Even Pronounce the Names of these Dinosaurs, and Jason was Telling Us” referred to parents being impressed at what their children can do when it comes to their CIs; “You Can't Change Them, You Can Only Love Them” was about the different styles of parenting that the parents employed in engaging their offspring on the topic of their interests; and “So I Can Do My Job at the Same Time and Observe the Weather at the Same Time” describes how the individuals themselves feel about their interests. These themes are reinforced with quotes selected by the author to demonstrate the results of this study. The discussion section will detail the specifics of the findings of this thesis.

## Chapter 4 – Discussion

The present study found five themes that were recurring in most, if not all, of the participants' stories. These themes provide more evidence to both potential problems resulting from overindulgence with CIs, as well as possible reinforcers for desired outcomes; it also found more evidence indicating the extent to which the capacity of an individual with an ASD's knowledge on their CIs can be of a robust and in-depth nature; elucidations of successful strategies for maintaining control of their offspring and countering potential drawbacks from overindulgence in their CIs; and reinforces the notion that the perspectives of the individuals with ASDs should not be ignored as the CIs are very important to their lives. Both parents and the individuals with ASDs themselves were generally positive about their interests in respect to what their individual futures held. While such a concept was apparent in the words of the individuals themselves, parents also remained relatively positive and optimistic about their children. The parents tended to see (or preferred to see) their children's disabilities as being manageable, albeit difficult and challenging. When the interests were detracting from socialization and task completion, the parents were encouraged by how they were able to control the situation. Most of the parents generally thought that their children's interests were not particularly debilitating, and thus did not comment much on how those interests could possibly affect their children in the future, if they commented on that issue at all.

The first theme was “*He's Very Unique*” and described generally positive responses from participants. “*He's Very Unique*” is similar to one of the themes found in Mercier et al. (2000), who highlighted positive aspects of the CIs. In the Mercier et al. (2000) study, the interests presented opportunities for happiness and pleasure, and in some cases even helped engage in interacting with others.

*“He’s Very Unique”* was a heavy and in-depth theme. As such, it was divided into two sub-themes. The first sub-theme was *“They Do Every Single Thing Together,”* which refers to situations where the interests that an individual with an ASD had were helpful in that person’s ability to socialize. These interests spurred the individuals to connect with others regarding their own interests with their typically-developed peers and helped facilitate appropriate social attitudes and actions. *“They Do Every Single Thing Together”* has some relation to the findings of Mercier et al. (2000), who found that the restricted interests contributed to several positive aspects, though the authors note that there were noticeable negative consequences to the interests as well. Despite the similarities with Mercier et al.’s (2000) study, this theme has more in common with the findings of Boyd et al. (2007). In the Boyd et al. (2007) study, individuals with ASDs could choose between an item that belonged to their own CIs or that of a less preferred item, and compared that with how often they would interact with other children. They found that all three participants would engage in higher levels of social interaction when the item in question was one of their own interests (as opposed to the less preferred item) and that they would spend more time with a peer who had an item related to their CIs. While parents in the present study did not state any incidents where their children would be more motivated to interact with others with their interests, in one case there was a scenario where the interests facilitated an interaction. As stated earlier in this thesis, Travis Jackson had an incident at an air-plane museum once where he immediately adjusted to a new child coming into a model airplane (scaled to children’s size), referring to the new child as his “co-pilot.”

*“He’s Very Unique”* had a second sub-theme, entitled *“Have You Seen All the Star Trek: The Next Generation Episodes?”* The description of this theme included incidents when the individual’s CIs helped motivate that person in performing necessary tasks. These

tasks were limited to the constraints of daily life including schoolwork, homework, employment, household tasks, and other societal and familial obligations. Unfortunately, to the author's knowledge, this topic has not been looked into very thoroughly from the perspective of using CIs for motivational purposes. Most of the literature focused on either the negative aspects of CIs or looked at the use of CIs for the encouragement of social interactions. There have been a few works that have looked into this issue, or at least found results that are similar to this theme: Mercier et al. (2000) mention that one of the positive aspects that they found in their study was that, for two of their six participants with an ASD, the interests provided a source of validation, with one participant pointing out that his interest gives him something to “master” and to “be responsible for it,” a topic that was echoed by that participant's parents. Those same parents also regarded their son's abilities with cartoon and geographical etchings garnered the respect of others, and the improved writing that was associated impressed his teachers. The parents in Mercier et al.'s (2000) study also pointed out that they were an incentive for personal and intellectual development, as their son began to learn more about the world by doing so; a similar sentiment, on the idea of self-growth, was echoed by the parents of another participant with an ASD in the Mercier et al. (2000) study. Attwood (2007) delves into this topic as well, outlining advice for constructively using and applying the special interest, including for motivational and learning purposes, employment, for making friends, and even as a part of cognitive Behaviour Therapy. Recently, this subject has been expanded on as the subject of the book, *Just Give Him The Whale* by Kluth and Schwarz (2008). Kluth and Schwarz's (2008) book outlines 20 ways that teachers can use the interests of their students who have ASDs so as to motivate and help their students. Some of the ideas that Kluth and Schwarz (2008) put forward for what teachers can use their students' interests for include enhancing in

particular subjects such as literacy and mathematics, encouraging social interaction, minimizing anxiety, inspiration, and happiness.

The second theme this study described was entitled “*They Don’t Realize that Not Everyone Lives and Thinks the Same Thing All the Time.*” It described responses that would be construed as not as positive, and would possess some detriment to that individual's ability to integrate and adapt to societal expectations. While Mercier et al. (2000) found both negative and positive aspects of CIs, those negative aspects were not as abundant as the positives, with descriptions of the negative aspects taking up less than a page, while the positive aspects took up over a page and a half. They found that half of the participants with PDDs in their study were aware of the invasive nature their interests led them to, that some of the interests were stressful for their families, that all the families reported that their interests were too focused on those specific topics, and that they had repercussions for various aspects of the lives of their family members.

Sometimes an individual with an ASD possesses a CI that, when engaging with that interest, produces outcomes that are not conducive to socialization. Those instances were described under the sub-theme entitled “*He’ll Stop People in the Street and Lift Up Their Pants to Look at Their Shoes*” and might include situations where peers and strangers would potentially become irritated by interaction with that individual due to how that individual expressed his/her desire for his/her CI(s). Several studies in the literature had some common ground with this issue of impacts on socialization, including Mercier et al. (2000), Klin et al. (2007), and Winter-Messiers (2007). Mercier et al.'s (2000) findings were predominantly positive, but they did find some negative aspects as well: the relatives of the individuals with ASDs confided that their kin's interests were too exclusive, and thus they tended to keep to themselves. In addition, half of the six participants in Mercier et al.'s

(2000) study who had an ASD admitted that they thought their interests were too invasive. In Klin et al.'s (2007) study, they found that the interferences of activities involving or with family members, peers, and other adults, is similar to this sub-theme. Several parents in the Klin et al. (2007) study pointed out that their children's interests can be self-absorbing, and they thus do not seek out contact with others in the same way that individuals in the non-developmental disability population would. Winter-Messiers (2007) found that the theme of social skills involved participants reporting that they were more cautious about bringing up their interests to others, describing anxiety about doing so, as well as a fear of rejection. This fear was strong enough in some children that they would identify interests common in their similar-aged peers without DDs, when in reality their true interests were hidden as they were not acceptable with their peer groups. In the present study, no participant mentioned such an idea, though some participants expressed concerns about interacting with peers, though this was largely the parents themselves and not the children. Kathy reported that her youngest did not see any problems enjoying shoes or dressing like a girl; Emma reported how her son would ask inappropriate questions about a person if he learned they had a medical procedure and did not seem to grasp that this was awkward; Walter confessed – and his mother reaffirmed – that he preferred his games of dinosaurs to the other children's games of Star Wars.

The sub-theme “*Could You Ask Calvin to Leave Mario and Dr. Octagonapus at Home? Cause it's Interfering with His Learning*” refers to incidents where the individual's interests interfered with his/her ability to perform certain tasks, including work and chores. Klin et al. (2007) found similar results: they found that the interests of their participants would affect the participants in such a way that it had an impact on others around them between 25% to 75% of the time. In the context of their study, this issue was most



significant in regards to self-directed learning, as numerous parents in the present study reported that their children's interests had a detracting value to their abilities to do certain tasks, such as learning.

*“Look, Mom! It's Eating It!”* was the final sub-theme regarding the negative effects of unregulated engagement with CIs and specifically refers to situations where the CIs had disruptive consequences. While these were not serious scenarios, nor scenarios that would necessitate intervention by the legal system, they were still concerning to the parents who described them. Future occurrences without the intervention and correction that the parents gave could have been more compromising, but at their worst they were troubling, embarrassing, or could have posed a more dire problem in the future (e.g., Leonard as a child would engage his curiosity in unique and disgusting ways, such as mixing his stool with various fluids, or playing pranks with his grandmother's false teeth, but as he aged – and with the guidance from both his mother and the special needs camp he went to – he does not display such disparaging behaviours as an adult).

Woodbury-Smith et al. (2010) conducted a study that had findings that merit mentioning with respect to *“Look, Mom! It's Eating It!”* and disruptive consequences in the pursuit of CIs. However, while the Woodbury-Smith et al. (2010) study dealt with criminal offenders with ASDs, none of the participants in the present study described criminal scenarios. This difference could, at least in part, be due to the young age of the majority of the participants in this study – while children may perform mischief during periods of neurological and cerebral development where they are unable to properly comprehend the ramifications of such mischief, they are seldom in an opportunity to be in conflict with the criminal justice system.

In the Woodbury-Smith et al. (2010) study, they found that most of the offenders

with ASDs interviewed had violent interests, as compared to a control of individuals with ASDs who did not have a criminal record. Despite that finding, they also found that almost three-quarters of the participants who were offenders did not have interests tied to their offences (e.g., non-violent interests included several examples, such as electronics, board games, nature, Japanese language/politics, and the offences included deception, harassment, assault occasioning actual bodily harm and grievous bodily harm (under UK law), assault, indecent assault, fake bomb threats, armed robbery, and arson). For half of the four offenders that did have a violent interest, they did not have any interaction with their offence/interest in real life, but rather they experienced that interest through reading. While it was the intent of the present study to see how CIs would impact the social and task-performance related aspects of their lives, the “*Look, Mom! It's Eating It!*” sub-theme emerged due to the frequency with which parents reported issues that were more pressing than problems with socializing and getting work done, but that were nevertheless nowhere near the severity that they would be in conflict with the legal system. For example, the reactions that Graham and Jason would have to seeing nature-related videos on TV and on the Internet prompted intense sorrow in Graham, to the point where his mother previews the programs to see if any frogs are harmed or eaten; whereas Jason's curiosity was piqued and his mother was disgusted by the video he was watching of a python eating a bovine.

The third theme this study found, “*We Couldn't Even Pronounce the Names of These Dinosaurs, and Jason was Telling Us,*” describes situations where parents were impressed by their offsprings' abilities. These abilities were linked to their fascinations and represented the kind of endeavours that can be associated with people with ASDs. In the Mercier et al. (2000) study, all of the participants who were family members of the participants with ASDs had some good things to say about their relative's interests, with

one exception: one of the participants had a brother who was the only participant in that study to offer nothing positive about his sibling's interests.

The fourth theme in this study was “*You Can't Change Them, You Can Only Love Them,*” and describes the different parenting styles that the parents in this study employed in how they raised their children. It also highlighted the feelings that the parents had in regards to the difficult but rewarding task of raising a child with autism. This theme echoed some of the findings in Winter-Messiers (2007). Parental perceptions by the participants of Winter-Messiers's (2007) study found that the CIs of their children were for fun, relaxation, task-avoidance, avoiding thinking about other things, self-calming, and stress/anxiety reduction. These ideas were also described by parents in the present study. That the CIs were a source of fun/relaxation was echoed by all participating parents whose offspring had interests strong enough to be described as CIs. None of the parents identified self-calming specifically, nor thought avoidance. Task avoidance was referred to, but it did not appear to be the intent: more often, their avoidance of tasks was an effect of the interest, and not an intent of engaging the interest. (i.e., a person with an ASD would engage in their CI and by doing so would automatically avoid the task, as opposed to engage in the interest so as to avoid the task). Jason's parents and grandfather reported that Jason would casually insist (as if he had a choice and was making one) on engaging his interests (e.g., staying on the trampoline or the computer) than eat dinner or whatever else they needed him to do. By contrast, Charles' engagement in the weather would sometimes leave him on the computer for hours, not thinking about any tasks that needed to be done. Several parents did report that their children would reduce their stress/anxieties by pursuing their interests. In both the present study and in Winter-Messiers (2007), when the parents voiced concerns, the primary reasons were that the interests were either socially inappropriate, not age

appropriate, and would not develop into careers.

Parents voiced concerns that were “negative” if they were socially inappropriate. Whereas Kathy had confided that her eldest son, Graham's, interests were generic so his interactions with others were more positive, her youngest son, Lyle's, interest in shoes was concerning because it was “girly.” Betty pointed out how her boys' conversations with friends would revolve strictly around their own interests. Victoria and Richard repeated similar ideas about their son's preoccupations and how he would “basically bore them to death with... rocks and stuff.”

The final theme found in this study was, “*So I Can Do My Job at the Same Time and Observe the Weather at the Same Time.*” It described the individuals with ASDs' perceptions of their own CIs, offering those participants an opportunity to further convey their own thoughts regarding their interests. Ignoring or down-playing the opinions and points of view of the people directly affected with an ASD is a problem as it overlooks an important source of information and is demeaning to people with disabilities. This thought-process in the academic literature has begun to wane in the past decade or so, and has in recent years come to be more oft enquired. One of the earlier studies to take this into account was Mercier et al. (2000), who found that individuals with ASDs would describe their interests as sources of pleasure, happiness, and relaxation and that they saw them as hobbies, ways to occupy time, and to avoid boredom.

In all the cases where the parents reported the presence of CIs, they also confirmed that the intensity and passion of those interests held significant sway over their lives. Mothers such as Emma Bidan and Maria Britannia went into great detail about the passions their children held for their CIs – for example, Maria's son, Calvin, despite being low-functioning and not being fully capable of verbal interactions, would sing to his heart's

desires alongside his favourite Disney movies. The children felt that CIs were important aspects of their lives and displayed an in-depth knowledge of their topics. Leonard O'Neill was vociferous in his defence of his interests, and young children like Walter Sweeney and Jason Lewis could demonstrate their interests in zoology (including dinosaurs) quite easily.

### *Limitations and Future Considerations*

There is no such thing as a perfect study, and the present one is no exception. The interviews revealed that not all the individuals with ASDs had a CI. In those cases, they were from two of the three females described in this study (Kyla and Tammy Testarossa), who were diagnosed as having PDD, while another individual that lacked a specific CI was a young male (Jake Archer) who was diagnosed with an obscure and unfamiliar form of autism that could not be verified in the academic literature. The majority of those participants who did have CIs were either diagnosed with autism or Asperger's syndrome, with the exception being Charles Bidan, who had a strong CI for the weather and was diagnosed with PDD-NOS.

Despite not having interests strong enough to be described as circumscribed, the results of these three individuals were still kept for several reasons. Predominantly, the reason they were kept was that their answers still provided valuable insight into the interests of individuals with developmental disabilities. It was also felt that it would have been rude to either leave those families in the midst of an interview, particularly for having the “wrong” diagnosis, nor was it deemed ethical to abandon their results completely just because the data they provided did not fit perfectly with the author's preconceived notions of such diagnoses. When the interviews were being conducted, the author was not cognisant of information indicating that PDD-NOS was considered part of the autism-spectrum (Matson & LoVullo, 2008; Ring et al., 2008), nor that one definition of ASD

(Matson & LoVullo, 2008) was identical to the DSM-IV-TR's criteria for PDD (APA, 2000).

Another limitation to this study is that there was no objective method of determining if an interest was “circumscribed” or not. While this would have been beneficial, the fact that this was a qualitative study put emphasis on the experiences of the individuals and did not require such lengthy rigour for this particular instance; it was also beyond the scope of this study to administer the kinds of tests that would assess if an interest was circumscribed. Objective methods of determining CIs have been attempted in previous research, and will be explained in the following paragraph. In the present study, participants were deemed to have an interest described as a CI if it was felt subjectively to be strong enough, often being reinforced by lengthy discussions by the parents or the individuals themselves. The result of this interpretation was the provision of rich data, often with the parents stating problems regarding social skills or ability to complete tasks/duties, or lauding the benefits they saw from the interests. These standards made determination of the presence of a CI more readily apparent when the participants would describe one or two specific interests in greater detail. Despite the lack of this quantitative procedure, almost all the families indicated at least one interest that was significantly stronger than those of their non-DD peers. The outliers were from the Testarossa family, as the two daughters did not have a circumscribed interest, but their overall experiences, as expressed by their mother, still provided useful data.

There are a lack of more objective methods of determining if an interest is strong enough to be a CI or not, which has forced other authors to rely on other methods. Some authors, like Winter-Messiers (2007) and Boyd et al. (2007) improvised their own methods: Winter-Messiers (2007) used a self-report questionnaire that she created for her own study,

while Boyd et al. (2007) identified the predominant interest as a CI when they received independent identification of that interest from two separate sources (in the context of their study, they had mothers participate for all three children and had either a teacher or a teacher's aide as well). While Cuccaro et al. (2007) focused on RRBs and not just CIs, they utilized the ADI-R to assess the specific diagnosis, and the Repetitive Behaviour Scales-Revised (RBS-R) by Bodfish, Symons, and Lewis (1999) to assess repetitive behaviours. Woodbury-Smith et al. (2010) noted this same problem of a lack of standardized tests of CIs and resorted to using their own semi-structured interviews for collecting the data they needed. While they did use the ADI-R from Lord et al. (1994) to assess the diagnoses of ASDs, they noted a lack of resources for determining if an interest is circumscribed or not, pointing out that the Cambridge University Obsessions Questionnaire (CUOQ) by Baron-Cohen and Wheelwright (1999) came closest for their needs but was still unsatisfactory. Woodbury-Smith et al. (2010) point out that the CUOQ focused too much on physics, did not allow for collection of sufficient data in any other circumscribed areas of interest, did not assess intensity of the interest, and referred to the interests as “obsessions” in the same erroneous and lay terms that are described below. By contrast, Klin et al. (2007) used the Yale Survey of Special Interests (YSSI) by Klin and Volkmar (1996), which served their purposes well. The YSSI is an open-ended questionnaire that elicits answers about the interests of children with ASDs and the extent with which they dominate the child's abilities to learn and communicate (Klin et al., 2007).

South, Ozonoff, and McMahon (2007) investigated RRBs as a larger group, though they did investigate CIs as well as other RRBs, such as motor movements and routine rigidity. In their study, they looked at the relationship between RRBs and secondary symptoms of autism, specifically executive functioning and central coherence. They used

the Repetitive Behaviour Interview (RBI) by Turner (1997) and the Yale Special Interests Interview (YSII) by South, Klin, and Ozonoff (1999). Much like the authors in the above paragraph, South et al. (2007) also found problems with measurement related to the study of repetitive behaviours. They point out several issues that impair measurement of RRBs: there are no instruments to measure both CIs and motor stereotypies; that some RRBs are best measured in terms of their frequency and their duration, whereas others are better measured in terms of the impairments that arise resultant to their engagement; and there is nothing to directly compare different RRBs and still be consistent and meaningful. They also found issues in investigating the complex relationship between RRBs and complex cognitive functions, such as the magnitude and difference between of the two topics, and how related studies previous to their own tended to focus on one aspect at cost to the other.

The genesis of this lack of an operational definition for what the interests should be called stems from a lack of consistency or standardization. The year 2007 had a number of studies that this thesis relied upon, but even at that time, the literature was still lacking a standardized name for the interests, much less an operational definition. When interest in CIs began a renewal in the latter part of the 20<sup>th</sup> century, the most prominent terms, as noted by Klin et al. (2007), were “obsession” and “compulsion.” These terms were used to refer to the interests despite the fact that the DSM makes it clear that the kind of obsessions and compulsions as found in Obsessive-Compulsive Disorder (OCD) are irrational fears or actions that require repetition, lest they cause distress in the person (APA, 2000). By contrast, Klin et al. (2007) point out that these interests are enjoyable topics that bring pleasure to their adherents; in a way, the older terminology for CIs is the complete opposite of what they actually are. This comes to no surprise, as prior to the time of Mercier et al.'s (2000) study, CIs were seen largely as a negative occurrence. It is only natural that the



language would reflect an uninformed view of this phenomenon.

Other studies besides Klin et al. (2007) point out a lack of consistency in nomenclature for CIs, and thus the lack of an operational definition, but there seems to be little advice for correcting such a deficit. While the names range from circumscribed interests (e.g., Boyd et al., 2007; Klin et al., 2007; Woodbury-Smith et al., 2010), special interest areas (Winter-Messiers, 2007; Winter-Messiers et al., 2007), and restricted interest (Attwood, 2007; Mercier et al., 2000), Mercier et al.'s (2000) nomenclature is distinct in that they looked at CIs from the perspective of the time, lacking the kinds of definitions we have now, and utilized the criteria of a restricted interest from the Autistic Diagnosis Interview (ADI), published by Lord et al. (1989), as they found that the operational definition of a restricted interest in the DSM-IV (APA, 2000) to be less detailed. Winter-Messiers (2007) collected numerous names used in the recent past to refer to CIs, most of which were from the 1990s or early 2000s. They also echoed Klin et al. (2007)'s concerns about the misnomer usage of obsessions and compulsions to refer to interests.

A final area of note is the reinforcement of a very important issue with regards to the distinction between quantitative methods and qualitative methods in science. A more empirical method of determining how far one can extrapolate the outcomes of a study involves being able to apply the methods of the study and recreate similar conditions with each performance, regardless of potential confounds among the participants in each sample. As such, a randomized sample is preferred, as it helps to overcome selection bias, and overcome other issues that might affect each individual circumstance, and apply the overarching facts from each representative sample to the population at large. As the study of autism focuses on a particular sub-group of humanity, it automatically negates a randomized sample under the conditions of this study as the researcher is forced to pick

and choose participants; this is further made more difficult as it becomes harder to find volunteers who are willing to share their personal lives in detail. However, qualitative methods are not intended to generalize results, as they focus on individual cases and pertain only to those individuals in the study. It is thus important to elaborate that the results of this study – as the participants were not solicited via random sample, and the study was not conducted with quantitative methods – should not be generalized to the larger population of individuals with ASDs.

### *Strengths of the Study*

Although there were some limitations, this study was beneficial in several ways. It is one of the few studies to investigate CIs, one of even fewer that did so through qualitative methods, and to the author's knowledge, is the first to do so from a phenomenological point of view. Second, this study looked at two specific areas that CIs can have a major effect when it comes to individuals with ASDs, interactions with others and performance of tasks. Other studies have addressed similar issues, or covered these issues in a broader framework, such as Mercier et al. (2000) (who did the first study on CIs in a qualitative framework), but most have not directly addressed questions on the aspects of social interaction and task performance. Instead, some have looked at more specific aspects, such as how CIs can be used as motivators (e.g., Winter-Messiers et al., 2007). Others have only done exploratory work into CIs that, while beneficial for providing data for the literature, have not addressed in sufficient detail how socializing and duty-performance are affected by CIs (e.g., Klin et al., 2007). This study also sought to specifically incorporate the responses of both individuals with ASDs – specifically children – and their parents. Most work in the past has used only the individuals themselves as participants, with some (e.g., Mercier et al., 2000) doing interviews with other family

members as well.

Another strength of this study is sample size. While previous authors have expressed concerns from their own sample sizes, such as Mercier et al. (2000) and Boyd et al. (2007), the problem of small sample size has been addressed in other studies besides the present one, including Winter-Messiers (2007), and Woodbury-Smith et al. (2010). It should be noted that Woodbury-Smith et al. (2010) also recommend larger sample sizes despite having a large sample themselves ( $N=44$ ). Other studies in the literature did not have numbers this high in regards to children with either autism or AS: Boyd et al. (2007) ( $N=3$ ), Mercier et al. (2000) ( $N=6$ ), Winter-Messiers (2007) ( $N=23$ ), Winter-Messiers et al. (2007) ( $N=23$ ). By contrast, Klin et al. (2007) had a larger sample size of children with higher-functioning autism diagnoses, with  $N=96$ . In the present study, eight individuals with ASDs and another three individuals with other PDDs participated, and another five children with ASDs were described but did not participate.

Another positive aspect of this study was that it was part of a series of studies that are starting to show a trend. In previous research, CIs were seen as a negative, and the meaning that individuals with ASDs had for them was ignored (e.g., Mercier et al., 2000). While the author realizes that this negative aspect of CIs is still important to both research and practice, and probably a natural reaction to the presence of any restricted interest, he also envisioned that these would be present as well. That is why this study chose to remain relatively neutral and asked open-ended questions. All but the last interview question were neutral in tone, and that final question was phrased in such a way to elicit a response that would be deemed negative (i.e., spending too much time on his/her CI, and would hinder getting homework and household tasks completed), but also addressed any positive aspects, if the parent deemed either were present. In the course of the interview, however, this

question was seldom asked straight out, as the parents would address any such concerns themselves in the previous questions, effectively getting to the questioned material before the author could ask that specific question; this may be due to the inter-related nature of the questions being asked. Such a question was not asked of the individuals with ASDs who participated in this study.

While it was not an issue that was investigated in this thesis, the concept of added gains, or secondary gains, deserves to be addressed. Did the participants in this study gain other benefits from engaging in their interests? This topic is addressed in Attwood (2007), who talks about the possible function(s) of special interests. Attwood (2007) makes note of some of the effects that the special interests have on individuals with Asperger's Syndrome; some of these benefits include reducing anxiety, understanding the world, and relaxation. While Attwood's concept is distinct from secondary gains, there are similarities. In the context of this study, participants with ASDs engaged in their interests because they liked to do so; it was obvious from hearing the participants speak about their interests (or the parents speak of their child/children's interests) that these individuals became happy when they engaged in their interests. In turn engaging in their interests would reduce their stress and anxiety, and provide a calming effect for them. As to how many gains there are, and how much of an effect they have on the individuals with ASDs, continued inquiry and investigation is warranted and recommended.

*Trustworthiness.* The use of a trustworthiness section is paramount, so as to outline the study's reliability, validity, and other values related to rigour. A trustworthiness section, as described by Merriam (2002), is used to support the claim that the study's findings are worthwhile, and thus seven of eight of Merriam's (2002) issues are addressed:

Triangulation, Member-Checking, Reflexivity, Adequate Engagement in Data Collection,

Variation, Audit Trails, and Rich, Thick Descriptions. Peer Review is also addressed, but has yet to be properly performed in this thesis. In addition, the subject of prolonged engagement is also addressed, using Mertens and McLaughlin (2004) as a basis; this portion is addressed prior to the topic of audit trails.

Triangulation is the implementation of numerous participants in interviews regarding the same topic so as to elicit multiple insights into that topic and to mitigate the effect of [unintentional] bias from a single or limited number of sources of participants. Triangulation was not performed in this study *per se*, but there was one core feature that is used by triangulation that this study employed. The use of more than one source of information was employed by this study. Instead of just looking at what one group had to say, two groups of individuals were chosen for this study. The perspectives of individuals with ASDs were selected because their worldview is the most important, as they are the people with the interests and who have to deal with them and any associated issues on a daily basis. The parents were a secondary source, as they were the primary caregivers for these individuals, and their knowledge of those individuals was the next best source. In some ways, it is possibly more reliable, as they are not the ones with the CI, and are thus less biased in favour of the particular interest.

Member Checks were attempted to be employed in this study, but unfortunately not all of the participating families agreed to do so, or were able to. All participants were provided an opportunity to comment on the analysis, but few participants opted for this procedure. A total of three families performed member checks, and only one individual with an ASD completed the member check. None of the participants who engaged in member-checking their respective interviews had any concerns or issues, and individually agreed that they were accurate transcriptions of the events that had transpired.

The issue of reflexivity has been addressed a few times throughout this thesis. The author of this study has stated that while he does indeed have Asperger's Syndrome, he has addressed this issue to avoid contamination of the results and to ensure the reliability and validity of the results. It is understandable that there would be concerns, but such concerns are mitigated by the rigour of this study and the reflexivity employed.

Another criterion to assess reliability/validity in qualitative research (Merriam, 2002) is the issue of whether the engagement in data collection was adequate or not. It has been addressed previously in this chapter that one of the issues with previous studies of CIs has been smaller sample sizes. In this study, a total of 27 individuals participated in this study across 11 families; additionally, five individuals with ASDs (four males, one female among two families) did not participate, but rather their respective mothers participated in their stead. Among those who did participate, there were 11 individuals with ASDs (nine males, two females), 15 parents (four fathers, 11 mothers), and 1 grandfather. Due to a limited number of possible participants, these were the only families interviewed, and thus sufficient time was dedicated to those families in terms of data collection.

Prolonged engagement refers to the length of time necessary to obtain sufficient and quality data. Mertens and McLaughlin (2004) point out that no set rule on time length exists governing how long an individual should remain at one particular research site. Rather than a fixed amount of time, their advice is to depart when the researcher has found that his/her themes and examples have become repetitious as opposed to adding more to the data. Their advice, in relevant parlance with this thesis' particular circumstances, is to conclude an interview when there are no more questions to be asked, as the participants have either answered all the questions or they have provided all the information possible. In the case of the interviews conducted for this thesis, all interviews were performed until

the interviewer felt that he had acquired all the data that he could get. In most instances, this lasted roughly an hour or more; the most notable deviations were the O'Neill family's interview – which last for longer than two hours – and the Testarossa family's interview – which was short compared to the other interviews as the children of that family did not display any CIs and thus it did not take long to have all the interview questions completed.

An audit trail is used to show a detailed account of the decisions in the process of creating the study (Merriam, 2002). In this sense of the term, such data exists, both in what is provided in the thesis, and in previous documents and versions of the thesis. In a more literal sense of a “trail,” there exists numerous copies and versions, in both digital and in many cases physical forms, of the research prospecti prior to the study, of the data analysis, and of the individual chapters of this thesis. In addition, the original recordings of the interviews, the full transcripts of those interviews, the original patterns found in the transcripts and the data analysis that would lead to the themes found in this study, and the master quotes list are all available as a data trail for reference. For reasons of confidentiality of the participants, the author cannot make available anything that would identify the participants. The original recordings of the interviews will be deleted in accordance with Laurentian University's ethics requirements after this study has been completed.

A final component of a valid and reliable study is the use of rich, thick description. That detail allows for the generalization of the findings, and for the reader to be able to determine the extent to which the situation matches the research context (Merriam, 2002). The descriptions of the particular themes in this study are rich with both the important quotes outlining the themes of this study, and detailed analysis of those quotations. To articulate these descriptions, in addition to a master quotation list of approximately 20+

pages using small text size (about size 4, Times New Roman), several of the quotes, particularly those that were most interesting and those that either refuted or supported the ideas behind this thesis, were pulled from the list and integrated into the results chapter. For each quote, a detailed analysis of what the participant said, and possibly meant, was articulated, as well as an explanation about how the quote fit into the various themes of this study.

### *Recommendations for Practice*

The present study found mixed results. While parents had a tendency to elaborate on the negative aspects of their children's interests, they also did not see these instances as very detrimental. The parents also spoke highly of their children's interests in numerous circumstances, including those where their children were able to transcend initial limitations so as to perform tasks and interact with others, as well as displaying specialized knowledge and passion for their interests. All parents whose children had strong interests were able to ensure measures of reinforcement to counteract their children's desires and to keep their children from becoming disruptively involved in their interests, such as focusing on them to the exclusion of all else. However, the individuals with ASDs themselves also revealed that they had a strong attachment to their interests, so parents should be more open to using their children's interests as positive reinforcers for striving in socializing with other people, and for getting their various tasks and duties completed. Such a method of parenting is especially important for the children, as the mothers of the two adults with ASDs in this study testified that they were able to eliminate most of the serious problems related to the practice of their CIs.

The author recommends that further work be done in the field of CIs. One important reason is that not a lot of research is being done on the topic of CIs; however, the last two



decades have seen a growth of interest in this subject, with a stronger focus on qualitative research, and less of a focus on perceiving CIs as detrimental. More importantly, CIs can be utilized to properly motivate children with ASDs. In this way, parents and teachers can refocus the interests to have the children engage more in study and other topics that would require a greater deal of reinforcement. Thus these individuals can achieve more and have a greater interest in doing so. Other authors such as Attwood (2007) and Winter-Messiers (2007) also recommend similar implementations; the first major qualitative study on CIs (by Mercier et al., 2000) was one of the first studies to look at CIs away from a strictly negative paradigm. More research is clearly needed into CIs, but more should also be done for individuals with CIs as well.

Both practice and future research would be well-advised in helping to allow both individuals with ASDs and typically-developed population to understand each other and their customs better. For instance, the typically-developed individuals may not be generally knowledgeable about a specific individual's preferences and engage in a social custom that is normal to most, but uncomfortable to that person (i.e., physical contact as a symbol of affection). By contrast, a possible scenario for an individual with an ASD could involve doing something that many in that culture are told – or raised to believe – is not appropriate, and raises an important issue: is the problem due to the individual with ASD's deficits in societal integration, or is it due to subjective cultural beliefs and morals that may differ from a more Western context. For example, it may be innocuous to most for a child to play with beads, but if those beads are used in a religious ceremony that is alien to that individual's culture, it could create great controversy, even if the individual was unaware of that significance.

The issue of understanding each other is not just limited to the rare event. Major

battles of the culture wars can bleed into these topics as well. Of concern in this study was the perception that Kathy noted regarding her son, Lyle, who is fond of feminine fashion and shoes, who might be perceived as being gay. While it should be noted that Lyle's interest in women's fashion is not necessarily a predictor of future sexual orientation, it is easy to see how many would make the conclusion that this child possibly has a different gender identity. Lyle and his family could face increasing hardships, not just because of society's pressures to adapt and assimilate into the broader cultural whole at the expense of the individual, but also because of his interest itself if it does not undergo extinction as he ages. The problem is, of course, not due to the nature of his interest, but rather that he is a boy and there are many people alive today who are uncomfortable with violations of traditional gender norms, and there are a plethora of people who are still under the corruptible and disparaging influences of bigotry and homophobia.

#### *Recommendations for Future Research*

One recommendation for future research on CIs is the idea of neurological aspects. Mercier et al. (2000) described the use of retrospective and prospective studies to determine if there are any underlying neurological or cognitive mechanisms that back the genesis of CIs. Winter-Messiers (2007) described MRI studies to see brain states when CIs are engaged in VS times when they are not engaged in. Other recommendations include examination of interactions between individuals engaging in CIs in more naturalistic settings, specifically with more natural time intervals, as well as trying to find ways to encourage individuals to broaden their interests beyond their current scope (Boyd et al., 2007), and the use of more female participants with AS, as they are also under-represented in the research (Winter-Messiers, 2007). It is the opinion of the author of this study that this topic is quite fascinating. It is also the opinion of the author that, as CIs are enhanced and

extrapolated interests compared to the interests of the non-DD populations, that perhaps we could have greater understanding of ourselves as a species if we knew where these areas were in parts of the brain, in what way they differ from the typically-developed population, and even why. These things may help with autism advocacy; rather than continue in the rhetoric of “cures” and other such topics, we can move on to helping people with ASDs in a wide variety of areas.

The use of other groups that could provide various points of view would be beneficial to the literature as well. Teachers have been utilized in the literature, and the present study considered their inclusion, as they spend a great deal of time with individuals with ASDs but do so in a different environment from the parents of those individuals. Due to certain constraints, the present study was unable to accommodate the inclusion of teachers, as valuable as they would have been. Their continued contributions to autism research is encouraged.

Controlling variables were also identified as a concern for future studies. Mercier et al. (2000) suggested comparing different levels of severity of diagnosis and societal participation, as these factors might describe how the results in their own study may relate to how well their participants integrated into society. Klin et al. (2007) noted their restriction to individuals with ASDs, commenting on the presence of intense interests in other disabilities, and how this might be a good control. Boyd et al. (2007) emphasized that their observations were under controlled conditions, and that observations of social interaction with CIs would be more beneficial in naturalistic settings. In relation to this study, it would have been more preferable for a smaller age-range, and the possibility of investigating more severely affected individuals with ASDs is also recommended. It would have been more preferable for this study to have more individuals, but whether those

individuals were children or adults with ASDs, they would have provided additional intriguing information.

Another reason to increase research in this field involves a lack of consistency. As noted in the introductory chapter of this thesis, as well as previously in this chapter, not only are CIs under-studied, they also lack a standard name (Klin et al., 2007; Winter-Messiers, 2007). One of the intriguing factors about the prospect of working on this topic was the ability to see different CIs in their native environments, and the inclusion of what those interests were in previous studies was of great interest to the author. Of particular note were the works of Attwood (2007), Boyd et al. (2007), Klin et al. (2007), Mercier et al. (2000), Winter-Messiers (2007), Winter-Messiers et al. (2007), and Woodbury-Smith et al. (2010).

In comparing these works, several caveats were identified that provide credence to the present author's postulate that there should be more consistency in categorizing CIs. First, not all of these works were original studies on CIs – Attwood (2007) provides detail on CIs in a chapter of his book. Second, not all of the studies provided lists of CIs encountered in their research, though all of them did provide examples of CIs. Third, not all of these works categorized the CIs encountered in their research. Finally, in those studies that did apply categorization, how the authors categorized the CIs differed from study to study. The present author decided to use these works as a basis of how to categorize CIs, and compared them to the CIs identified in the present study. A new classification system was created, one that may be beneficial to future studies, as well as to consistency in the nomenclature of CI categorization. The categories for CIs, based on information from Attwood (2007), Boyd et al. (2007), Klin et al. (2007), Mercier et al. (2000), Winter-Messiers (2007), Winter-Messiers et al. (2007), Woodbury-Smith et al.

(2010), and the present study are as follows: academic topics/technology, lists/collections, unusual objects and other topics, sports/games, the arts, and entertainment. Using this classification system, the CIs (and, in cases where there was insufficient data to determine if the interests were CIs, the strongest interests) identified and described by participants in this study are listed in Appendix G and grouped by these new categories.

Various authors have categorized CIs in different ways. Often, in this author's opinion, in too limited a form. Attwood's (2007) categories are broad, which is useful but still limiting: they are grouped under either collections or the acquisition of knowledge on a specific topic or concept. To note, Attwood's (2007) categorization system is beneficial in that it underlines two recurring themes to CIs, in that these are what they tend to be. But the essence of what the interests are is not touched upon. He also notes that there are minor gender differences, namely that girls tend to prefer collections that are more familiar with the collections of females who are not developmentally different, and prefer acquiring knowledge that is related to fictional "facts" such as information regarding Harry Potter.

Other authors have found broader categorization schemes. Winter-Messiers (2007) identified eight common themes in the interests presented in her study, including transportation, music, animals, sports, video games, motion pictures, woodworking, and art. Mercier et al. (2000) described three categories that their reported CIs fell under, including collections, music, and knowledge/activities pertaining to very precise areas, bearing similarity to Attwood's (2007) categories.

The most important recommendation for future studies is that the nature of CIs is still not understood. There are many questions about how they come about and why they do so, and what their specific function appears to be. This idea is endorsed by some of the most prominent studies in this field. Mercier et al. (2000) desired to know if these interests

could be understood in terms of origin, explanation, and even maintenance and modification, as their study also looked at how the interests changed over time. Klin et al. (2007) pointed out that a better knowledge of CIs would help us understand the social, communicative, personal lives, and professional lives of people with ASDs, as well as if those interests could be better applied to society. Woodbury-Smith et al. (2010) noted that not just the nature of CIs is understudied, but so too is the relationship between the individuals with ASDs and the criminal justice system; specifically they desire to know if we can better understand the content of CIs, their pursuit, the meaning they have for the individuals, and the possibility of susceptibility to constraints in their lives.

The position of the author of this thesis is that there is a need to understand more about CIs, and more research is required. Said position is due to what was found in this study: for one, it reconfirmed the reality of CIs. They can be useful, such as motivating people with ASDs to interact with their peers, and they can serve as a detriment, such as making social integration more difficult with the constant barrage of speech related to their interests. Secondly, while this focus did have a stronger tone of concern for the drawbacks of having intense fascinations, parents were still optimistic about their offsprings' futures; this is supported by the two older participants in the study who were better at managing their interests as adults than as children. Finally, the very fact that this study generated the findings that it did serves as demonstration that more research is needed. The very nature of interests, in relation to autism and in relation to the general population, is fascinating. We still do not know why these interests are so strong, and why they have the level of devotion they do. Understanding why these interests are so strong might help us determine positions that have strong adherents and significant consequences to society at large, such as religious and political zealotry.

### *Conclusions*

CIs have several benefits, as well as several detriments. Their adherents can be motivated to perform necessary tasks, engage in interactions with others, and find them personally rewarding and entertaining. They can, by contrast, also serve as detriments to task performance and social interaction, as well as inspire actions that are not always acceptable. The individuals with ASDs that have these CIs see their interests differently from their parents. While they see their interests in a generally more positive – and less critical – frame of reference, their parents are by contrast more critical and more neutral in terms of preference to the CIs. Whereas they are more critical of the interests, describing numerous troubling scenarios, they were also wholly impressed by the abilities that their children had when focused on their interests.

CIs are not the demons they have been portrayed as in research prior to this millennium. They are strong passions that people with ASDs have for things in this world that make them happy, excited, intrigued, and curious. They have the ability to be utilized to great benefit. They can also, if left untreated, lead to deprivations in socializing and task performance, including work, school, and household chores. Continued research is necessary to better understand them, but we should always remember the human side of these topics. Continued research without respecting the values and rights of individuals who are, or who may be potentially at-risk or vulnerable would be a tragedy.

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## Appendices

### Appendix A

#### Interview Guide

##### Questions for Parents

- 1) Please describe your daily routine with your child.
- 2) What is your routine with preparing your child for school? After he/she comes home?
- 3) What are some of the interests your child has? Please elaborate on this interest to the best of your ability.
- 4) What have been some of your child's interests in the past? Please elaborate.
- 5) How does this interest preoccupy your child?
- 6) How does this interest affect your child's schooling?
- 7) How does this interest affect your child's social? With family?
- 8) How does this interest affect your and your family's social life?
- 9) How does this interest interact with his/her peers and/or teachers?
- 10) To what extent does your child preoccupy himself/herself with this interest?
- 11) What are some of the things your child does in regards to this interest?
- 12) Would you say that there are any aspects of this interest that you would consider disabling, hindering, or interfering with "normal" or near-"normal" functioning? Why?

##### To children:

- 1) Please describe your daily routine.
- 2) What are some of the things you are interested in right now?
- 3) What is it that you are most interested in right now?
- 4) Please elaborate on this interest as best you can.
- 5) How do you interact with your parents? With siblings? With friends and your peers at school? How do you interact with your teachers?
- 6) How often does this interest preoccupy you on a daily basis?
- 7) How do you think this interest interacts with your schooling?
- 8) Do you have any friends who do not have disabilities? If so, do you bring up this interest with them, and how often do you do so?

## Appendix B

### Sample advertisement in Bulletin Boards

**“Understanding Circumscribed Interests in Individuals with Autism-Spectrum Disorders and How They Relate to Families and School”**

Are you the parent of a child or children with autism?

Does your child have any strong interests in a particular subject?

Would you and your child/children be interested in telling your story?

If so, please contact David Gass, Master's psychology student at Laurentian University, at [dx\\_gass@laurentian.ca](mailto:dx_gass@laurentian.ca) for more information.

## Appendix C

### Recruitment Script

Hello all,

My name is David Gass, and I am a graduate student in Laurentian University's Psychology program, specifically the Master's of Experimental psychology application. My current research is on the circumscribed interests of individuals with autism-spectrum disorders. Your participation would be greatly appreciated.

Involvement is simple – participation in individual interviews with myself (the researcher) to understand your point of view of your child's (or children's) interests. This interview process is not limited to just yourself, as I am also interested in the viewpoints of the individuals themselves. As such, I would greatly appreciate the involvement of at least one of your children with an autism-spectrum disorder as well as yourself. Your children would be interviewed using very similar questions to what you would be interviewed with. My work would also benefit if I could have the prospective of your child/children's teacher from the previous school year.

There are no obligations binding you to this study, and you and your children reserve the right to withdraw from this study at any time without consequence. Breaks at any time can be used for whatever reason, including tiredness, bathroom breaks, and situations involving your child or children. You also do not have to answer all of the questions – if you do not feel comfortable with a question, you reserve the right to skip it or provide as minimal information as you see fit. There are no anticipated risks to participants. Should any discomfort arise, support services will be provided. Personal information gathered in this study will remain private and confidential and all data will be destroyed one year after completion of the study. This project has been approved by the ethics board at Laurentian University.

If you do choose to participate, please contact me at my student e-mail, [dx\\_gass@laurentian.ca](mailto:dx_gass@laurentian.ca). We will then schedule the time and location of the interview and you can then sign the consent form, which you are free to keep for your records. If you have any questions or concerns, please feel free to e-mail me at the above address, or contact Dr. Watson, my supervisor, at 675-1151, ext 4223 for more information.

## Appendix D

## Ethics Approval



**Laurentian University**  
**Université Laurentienne**

**APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS**  
 Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL	New	Modifications to project	Time extension	X
Name of Principal Investigator and school/department	David Gass (Dr. Shelley Watson; supervisor) — Psychology (Laurentian University)			
Title of Project	<i>Understanding Circumscribed Interests in Individuals with Autism-Spectrum Disorders and How they Relate to Families and Schools</i>			
REB file number	2009-07-02 R3			
Date of original approval of project	October 1 <sup>st</sup> 2009			
Date of approval of project modifications or extension (if applicable)	June 21 <sup>st</sup> 2010 (R1); June 1 <sup>st</sup> 2011 (R2); November 3 <sup>rd</sup> 2011 (R3)			
Final/Interim report due on	June 30 2012			
Conditions placed on project	Final or interim report on June 30 2012			

During the course of your research, no deviations or changes to the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please complete the appropriate [REB form](#). All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate [REB FORM](#).

In all cases, please ensure that your research complies with the [Tri-Council Policy Statement \(TCPS\)](#). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations, and best of luck in conducting your research.

Jean Dragon Ph.D. (Ethics officer LU) for Susan James Ph.D.  
 Acting Chair of the Laurentian University Research Ethics Board  
 Laurentian University

## Appendix E

Consent form (Parents and Individuals with Autism over 18 years of age)



**Laurentian University**  
**Université Laurentienne**

### PRO FORMA CONSENT FORM

**Study Title:** Understanding Circumscribed Interests in Individuals with Autism-Spectrum Disorders and How They Relate to Families and School

**Investigator:** David SJ Gass, B.A. (Hons)

I am a psychology master's student in the Graduate School at Laurentian University studying circumscribed interests - the intense fascinations that individuals with autism-spectrum disorders have on virtually any topic. Some of these interests include history, objects, or TV shows/movies. The study is intended to provide information about these interests, as they are not fully understood; this will serve to increase the awareness of these interests to parents, caregivers, and society in general. Your participation will involve an interview and should not take much longer than 1 hour.

Your participation in this study is entirely voluntary. You have the right to withdraw at any time without penalty. Though none are anticipated, if any distress or discomfort is experienced, support services will be provided.

If you have any questions or concerns about the study or about being a participant, you can call me at 698-1812 (researcher's telephone number) or you may address my supervisor, Dr. Watson at her office at Laurentian University, (705) 675-1151, ext. 4223 for information. You may also get in contact with me via my university e-mail account, [dx\\_gass@laurentian.ca](mailto:dx_gass@laurentian.ca). This would be the best method of contact as I check my e-mail account several times daily and respond quickly.

Your identity will not be revealed at any time. References to specific situations in my research will be safeguarded with the use of changed identities for all participants. All data will be destroyed one year after the end of the study.

---

By signing below, I (the participant) agree to participate in this study and I give consent for my child to participate. I understand that there is minimal risk involved, understand my right to withdraw at any point in time without penalty, and I have received a copy of this consent form.

---

Participant's Signature

---

Date

☐

I would like to receive a copy of the results of this study upon its

## Appendix F

Consent form (Individuals with Autism under 18 years of age)



### PRO FORMA CONSENT FORM

**Study Title:** Understanding Circumscribed Interests in Individuals with Autism-Spectrum Disorders and How They Relate to Families and School

**Investigator:** David SJ Gass, B.A. (Hons)

Hello, my name is David Gass. I am a psychology student at Laurentian University studying circumscribed interests in individuals with autism. These interests are the intense fascinations that most individuals with autism have. The research literature is lacking much work on these interests, and I wish to provide more information to the scientific community on them, which will in turn help your parents, teachers, and other people in your life better understand your particular syndrome.

Participation is simple, it only involves an interview that will take about 1 hour. Your participation is entirely voluntary, and you can choose to withdraw at any time without penalty. Should you experience any discomfort or distress, support services will be provided, though I can assure you that this is unlikely.

If you have any questions or concerns about the study or about being a participant, you can call me (or have your parents call me) at 698-1812 (researcher's telephone number) or you may address my supervisor, Dr. Watson at her office at Laurentian University, (705) 675-1151, ext. 4223 for information. You may also get in contact with me via my university e-mail account, [dx\\_gass@laurentian.ca](mailto:dx_gass@laurentian.ca). This would be the best method of contact as I check my e-mail account several times daily and respond quickly.

Your identity will not be revealed at any time. References to specific situations in my research will be safeguarded with the use of changed identities for all participants. All data will be destroyed one year after the end of the study.

---

By signing below, I (the participant) agree to participate in this study and I give consent for my child to participate. I understand that there is minimal risk involved, understand my right to withdraw at any point in time without penalty, and I have received a copy of this consent form.

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

☐

I would like to receive a copy of the results of this study upon its



## Appendix G

### List of Interests Articulated by Participants of this Study

#### Academic Topics: Science

Chemistry

Medicine

Meteorology/Weather

Biology (including: Dinosaurs, Tarantulas, Bird-watching, Animals (modern), Frogs, Gardening)

#### Academic Topics: Mythology/Literature

Lycanthropes

Dragons

Books

#### Academic Topics: Mechanics/Engineering

Architecture

Cars

Airplanes

Airplane crashes

H.M.S. Titanic

#### Collections:

Yu-Gi-Oh! Trading Card Game

Shoes

LEGO blocks

#### Entertainment: Television/Movies

Thomas the Tank Engine

Star Trek (particularly The Next Generation)

SpongeBob Squarepants

Fairly Oddparents

Walt Disney movies (particularly their songs)

#### Entertainment: Games

Computer Games

Video Games: (including Nintendo Wii and Sonic the Hedgehog)

#### The Arts:

Drawing (including comic strips and manga form)

Plasticine sculpting

Home movies

#### Sports:

Wrestling